A SENSE OF SELF: RECONCEPTUALIZING AUTOIMMUNITY

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BY
MONIKA CWIARTKA, B.Sc., B.A.

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AUTHOR: Monika Cwiartka, B.Sc., B.A. (McMaster University)

SUPERVISOR: Dr. Sarah Brophy

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Abstract:

In its essence, this thesis is concerned with how the language of immunology affects eventual patient conceptions of self. Specifically, I examine how biomedical discourse affects both the mental and physical experience of autoimmune disease.

Typically described in militaristic terms as an 'attack on self,' autoimmunity, (when an individual's immune system responds to 'self' tissues), encourages the following questions: what is self, in a biological sense? What is the effect of medical intervention on a patient's sense of selfhood, when the offending other to be removed is actually an integral part of one's own body? Is there a mental readjustment of what constitutes selfhood in the wake of such a diagnosis?

In my attempt to answer these questions I have divided the thesis into three chapters. Chapter one is an exploration of the semantics and methodology of basic biomedical research, eventually culminating in a discussion of two different paradigms of immunity currently in operation. One of the main points of this thesis is that scientific representations of the body are indeed constructions, rather than reflections of the truth of our selves, and that these constructions are in constant flux. By comparing and contrasting two different immunological paradigms used to frame research and articulate the body, I aim to show how different the mental body could be according to which paradigm is followed. In particular, I want to show that autoimmunity is not necessarily an attack on self, or a rejection of self. This thesis is therefore also a search for a 'better' metaphor for autoimmunity that does not involve the rejection of the diseased self.

Chapter two examines the language of immunology from a cultural perspective. Paradigms of the immune system have their roots in cultural ideology as much as in the laboratory. This chapter aims to show how research and sociopolitical and economic systems serve to mutually reinforce a common view of 'reality.'

Chapter three then looks at personal narratives of individuals living with autoimmune disease in light of how basic research methodology and culture construct and treat disease and the diseased individual.

By showing the link between supposedly objective science and the personal experience of illness, I am hoping that work such as mine affects not only patients that might be grappling with confusing diagnoses and searching for alternate ways of conceptualizing their diseased bodies, but also how scientists and medical practitioners explain the body to others.

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Contents:

Introduction:

Although illness and the workings of the immune system have fascinated and baffled humanity for centuries, at no other point in history has immune system discourse so thoroughly permeated a culture. As Jackie Stacey points out in *Teratologies*, her study of metaphor in cancer and its personal and cultural impacts, "Whether imagined as a battlefield, a communication system, or a network of mirrored and distorted reflections, or a combination of these, the immune system is one of the most significant forms of scientific 'discovery' to have influenced popular perceptions of our bodies and out health in the last twenty years. Immune system imagery pervades numerous and diverse aspects of our contemporary culture" (163). Something has happened, particularly in 'first world' cultures, over the past twenty or so years to make terms like 'T cell' almost part of our colloquial language. Perhaps widespread education initiatives elucidating the mode of HIV infection have something to do with mounting immune language competency. Or perhaps recent changes to how healthcare is managed and dispensed, "placing health firmly within a world of competition and consumerism" (Stacey 2), have allowed for pervasive 'education' initiatives (usually in the form of direct to consumer drug advertising). There is also the fact that scientists simply know so much more about the immune system (IS) than ever before. Suddenly the dizzy spells, the urinary incontinence, the momentary paralysis in one limb, and the blurry vision that would have simply been labeled 'hysteria' in another generation have an immune basis. Whatever the reason, one thing is certain - biomedical discourse has radically altered how we conceptualize our bodies and how we experience illness.

Throughout the thesis I will be using the term 'discourse' to mean, in its most basic form, language involving subjects who speak and write, presupposing listeners and readers as 'objects,' or recipients. In the case of biomedicine this refers to multidirectional dialogue between experts and patients concerning the (patient's) body - the former invariably the subjects who speak and write, either to other experts as objects (in which case the language used becomes highly technical and implies an exchange of information), or to patients as objects (implying literally that, the patient as *object* rather than linguistically capable equal). Increasingly, however, patients have begun to assert themselves as the *subjects* of biomedical discourse, typically in the form of personal narratives that presuppose mainly non-experts as recipients, thereby changing the experience of illness.

The importance of language in how we experience a given disease cannot be overemphasized. The way that a given disease is described is one obvious way in which language affects the experience of illness.[1] In this respect the past fifty years have been especially important to current notions of disease and illness. Since Frank Macfarlane Burnet formulated in 1959 that B cells are activated to produce antibodies by interaction with a foreign pathogen, a view of the immune system has progressively emerged where

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[1] It is important to note here that the phrase 'the experience of illness' is not merely referring to the experience, and subsequent treatment of, the particular physical manifestations of a disease; illness is not simply the sum of symptoms. Rather, illness is the experience of a given disease in a cultural context. Sontag's *Illness as Metaphor and AIDS and its Metaphors* does a great job of examining tuberculosis, cancer, and AIDS in their cultural context - and in particular, showing how the experience of these diseases has changed over time.

the distinction between 'self' and 'nonself' is its main objective: self is to be 'tolerated' and nonself to be attacked. Setting the possible political origins of such a paradigm aside for later, what this means is that disease is therefore described as a battle against foreign invasion, the body as a kind of fortress (or a passive battlefield), immune cells as the army, and the patient as? And here it gets tricky, since this kind of military analogy of disease posits the patient as (potentially simultaneously) a multitude of things - passive victim to be defended by medical expertise, traitor in league with the foreign enemy (especially in the case of autoimmune disease), active 'fellow in arms' with medical expertise ('we can fight this thing together!'). And depending exactly on how a given disease is articulated to and by a patient, it will influence both the patient's conceptualization of themselves, their interaction with caregivers and medical expertise, and also how medical experts in turn relate to the patient. The aim of this thesis, broadly, is to examine how biomedical discourse has affected, and complicated, the experience of autoimmune disease.

Multiple Sclerosis (MS), probably the most recognized autoimmune disease (AID), is currently described as an immune attack on the myelin sheath that surrounds neural axons, leading to demyelination, incomplete remyelination, scar formation, and diminished neural-muscular coordination. Similarly, Systemic Lupus Erythrematosus is described as "chronic IgG antibody production directed at ubiquitous self antigens present in all nucleated cells" (Janeway 12:10), including cellular DNA itself. In non-insulin dependent diabetes "the insulin-producing B cells of the pancreatic islets are selectively destroyed by specific T cells" (Janeway 12:14). And in Graves' disease "autoantibody to the thyroid-stimulating hormone receptor on thyroid cells stimulates the production of excessive thyroid hormone" (Janeway 12:9). And there is a list of literally hundreds of such instances of the immune system attacking 'self.' In fact, in *At War Within: The Double-Edged Sword of Immunity* (1995), William R. Clark describes autoimmunity as "not an accidental spillover of damage in the course of trying to remove a cryptic pathogen but *true aggression* against perfectly normal, healthy self cells" (120, emphasis mine).

When this project was originally conceived I wanted to examine how such articulations of autoimmune disease - as an attack on self - subsequently complicated notions of selfhood: if 'you' are supposedly attacking yourself, then what, or where, is the real self (in a conceptual sense)? When immune discourse frames all disease as the defense of the greater self by an immunological self (T cells, B cells, etc) from an invading 'other,' then even in instances of autoimmunity (where there is no invading other *per se*) something must become other. Thus, either the immune system becomes other and the terrorized body becomes self, or the target tissue, cell, molecule or protein becomes other and everything else remains self, or the whole body becomes the enemy and selfhood is displaced onto a nebulous soul.

Inspired by Sontag's dedication towards an elucidation of, and subsequent liberation from, the "lurid" metaphors that make the experience of illness so much more awful, I also decided that as part of this project I would attempt to propose an alternate way of conceptualizing autoimmunity, one that does not entail fragmentation or rejection of any component of self, and one "purified of, [...] metaphoric thinking" (Sontag 3).

However, the more I delved into various critiques of biomedical discourse, the less confident I became that it was possible to separate metaphor from illness. What feminist critiques of semantics have taught us is that the moment something enters the realm of language, it also enters the realm of culture and ideology. I am assuming the alternative that Sontag envisions would portray illness in strictly objective biological terms. However, as the first chapter will demonstrate, the term 'objective science' may be somewhat of an oxymoron: the moment a band on an acrylamide gel representing a protein fragment becomes translated into word, and woven into the body story, science ceases to be objective. Furthermore, even the methodology itself, the *way* the data is gathered is influenced by culture and ideology. Perhaps the more realistic, and productive, approach then is to recognize the potency of language in mediating the experience of illness, and that virtually every representation of the body and the immune system *will* be a metaphor, but that some will be 'better' than others. Thus, this thesis is the search for an alternate *metaphor* for autoimmunity.

I have chosen to begin the discussion with an exploration of how basic biomedical research contributes to the construction of the body story (the term I will be using to denote *conceptual* notions of what constitutes a body and how that body functions on a physical level). Most believe that the experience of illness begins with the diagnosis, and hence with the doctor-patient interaction. Although we are aware as a society that biomedical research, in a vague sense, must be taking place somewhere, (since we are continually bombarded with headlines stating that researchers have found the cure for this or that, or with pleas asking for donations so that more research can be done), it is not a world most patients are familiar with, and hence not thought to be directly associated with the private experience of illness. Research is the objective, invisible world of pipettes, test tubes, white sterility, and the irrefutable truth of numbers. How can such a world be biased? And since it is so far removed, literally, from the patient's experience, how can it contribute to the private negotiation of identity in the wake of the diagnosis? However, as Sue Rosser notes in her essay "Re-visioning Clinical Research: Gender and the Ethics of Experimental Design": "Since modern medicine is based substantially in clinical medical research, the flaws and ethical problems that arise in this research as it is conceived and practiced in the United States are likely to be reflected to some extent in current medicine and its practice" (127).

The decision to dedicate a chapter on the role of basic biomedical research in the eventual private experience of illness was based on two major factors: first, it is basic research that decides how a given biological process, or disease, will be articulated - or how flesh becomes word. The diagnoses and explanations that physicians offer their patients are based on findings in original research publications. Secondly, the notion of immunity as self-defense against foreignness is continually reinforced by the scientific findings. Ever since Burnet proposed his 'clonal selection theory' in 1959 immunologists have been primarily concerned with elucidating the *details* of immune system function within the framework of the self-nonself paradigm, rather than challenging it *per se*. As will be discussed more extensively in the first chapter, a paradigm is the collective understanding of 'reality' amongst certain individuals. The current dominant notion of reality among immunologists is that the immune system tolerates or ignores 'self' and attacks anything that it recognizes as 'nonself' - what has come to be known as the 'self-nonself (SNS) paradigm of immunity.' And it is precisely the existence of this paradigm that has made autoimmunity so conceptually problematic. Thus, an alternate explanation of autoimmunity must also begin at the level of immunological paradigm and must be supported by basic research.

Although thus far I have placed the mental conceptualization of the body as the final point along a linear continuum that begins with basic research, the way that culture and ideology influence biomedical research, and most importantly, vice versa, is actually better represented by a tangled web than a straight line - as all of the systems that construct our reality are linked to each other. The self-nonself paradigm that has framed the majority of immunological research has its roots in culture as much as it does in the laboratory. In chapter two I will explore how the SNS paradigm is reflective of a specific political climate that encourages strict adherence to prescribed roles, the othering and suspiciousness of foreignness generally, and fiction of the maintenance of purity within. The articulation of the paradigm, the precise terminology selected (namely military), can also be seen as reflective of social politics. In not so subtle ways, the immune system is a microcosmic portrayal of society. The second chapter therefore focuses not so much on *how* things are done (as in the first chapter), but rather on the language used to finally describe the body after the data has been amassed, the numbers crunched, and the graphs made, and particularly how the language selected to describe the immune system serves to reinforce the sociopolitical economic system in place. The description of autoimmune disease as "a chronic civil war within the body" (Aladjem), is not an accident, nor inevitable, nor 'natural.' There are technically innumerable ways of explaining the finding that in some instances specific immune cells interact (in a deleterious fashion ultimately) with body cells. Choosing to describe it as the "War Within" (Clark) is therefore as much about politics as it is about science.

The third and final chapter looks at personal narratives of patients with autoimmune disease. Although the order could have easily been reversed, the personal side of illness is examined last because the manner in which patients view and experience their illness will have significantly more meaning in light of the previous two chapters. The aim of this chapter has remained the same since its conception - to examine how the individual experience of disease is shaped by the various semantics of illness. As with any disease, the actual physical manifestations of the disease (the symptoms) represent only one fragment of the experience; how the disease is *conceptualized*, or imagined, in relation to identity becomes in many ways the more primary reality for the patient. Autoimmunity is particularly interesting to study in this way because there is such disparity between the physical and the mental experience of the disease.

Especially important in this chapter is the notion, inherited from basic biomedical research, that the body is the sum of its parts, and that modern medicine entails the isolation and extraction of undesired parts. Again, this is considerably complicated in the case of autoimmune disease because the semantics of medical intervention rests on the premise that disease is caused by a foreign agent. Speaking of isolation and extraction makes sense (to a limited degree) when this is technically feasible through antibiotics and surgery, but what happens when the 'culprit' is a complex immune-driven process inseparable from 'self'? In a broader sense the question being asked is how illness generally fits into one's identity when every aspect of biomedicine - from research methodology, to the paradigm used, to the political philosophy that led to the paradigm, to the way we communicate and interact - is centered on rejection of disease and hence rejection of the diseased other.

Since one of the main objectives of this thesis is to propose an alternate explanation of autoimmunity, introduced in the first chapter and featured throughout is an immunological paradigm very different from the SNS paradigm that has lead to the current conundrum with respect to autoimmunity. Developed by an immunologist named Polly Matzinger in 1994, the Danger Model (DM) completely rejects the assumption that the immune system's main objective is to distinguish self from non-self. Instead, Matzinger posits that danger, rather than immune xenophobia, determines whether and how the immune system responds: only those things that cause actual damage to the body require an immune response. What this means is that foreignness itself is not always bad, and self need not always be 'tolerated.' Most importantly for the purposes of this discussion, it means that autoimmunity can be explained in completely different terms to the patient, not requiring the rejection of any component of self. As with the SNS paradigm, the Danger Model is also not merely a way of explaining the immune system, but rather part of a larger system of knowledge and interaction, one potentially less encouraging of fragmentation. Throughout the discussion there will be a comparison of the two paradigms and a consideration of how both may ultimately affect the personal experience of illness in different ways.

Slowly a different version of the body is emerging, one respectful of the complexity and integrity of the system as a whole, rather than the sum of its parts. Potentially, wider medical acceptance of a more holistic version of the body will not only alter the experience of illness to make it less isolating and horrible for the patient, but also influence other systems of knowledge away from fragmentation and the rejection of otherness.

Chapter One: From pipette, to paradigm, to patient

> The higher intellect, the imagination, the spirit, and even the heart might all find their congenial aliment in pursuits which, as some of their ardent votaries believed, would ascend from one step of powerful intelligence to another, until the philosopher should lay his hand on the secret of creative force and perhaps make new worlds for himself. We know not whether Aylmer possessed this degree of faith in man's ultimate control over Nature.
>
> Nathaniel Hawthorne, "The Birthmark"

For most of us medicine means doctors, invasive diagnostic procedures, and ultimately, drugs. Certainly, as we patiently listen to the diagnosis, we do not question how basic research may have contributed to the manner in which the disease is explained to us, and how we subsequently conceptualize our bodies. Research is supposedly objective - scientists in white lab coats, carefully pipetting something from one tube into another, using complicated equipment to do complicated experiments that involve arcane specialties like genetic engineering. How can that not be purely objective? The notion that medicine is framed by the sociopolitical context is much easier to accept on the level of caregiving, since that entails a human component, than on the level of basic research.

What I aim to show in this chapter, however, is that the methodology itself, the actual pipetting, has cultural implications that go beyond the biological safety cabinet. A significant portion of the chapter will then focus on the paradigms and models used to direct this research, since at more advanced stages of any scientific discipline it is the paradigm that directs the questions asked and thus answers found. For most of the discussion of basic research methodology I will be drawing on scientific papers dealing with the subject of Multiple Sclerosis, although the observations made can easily be applied to other research areas. I chose MS because it is one of the most prevalent and socially recognizable autoimmune diseases. But also because disease progression is so unpredictable: some MS patients have a single episode with mild symptoms, some experience periodic mildly debilitating episodes that never progress to canes and wheelchairs, while others quickly suffer a complete sensory and motor breakdown that leaves them vegetative. The experience of MS thus varies widely from patient to patient, but the articulation and understanding of disease etiology does not, thus allowing for a discussion of how individual bodily and mental experience contribute to illness and identity, versus how generalized cultural notions of the disease affect how it is experienced. As Robin Franklin notes in her scientific review article "Why Does Remyelination Fail in Multiple Sclerosis" (2002): "The disease is complex - its aetiology is multifactorial and largely unknown; its pathology is heterogeneous; and, clinically, it is difficult to diagnose, manage, and treat" (705). Yet, despite the incredible variability of this disease, (no two patients will experience the disease in exactly the same way), it is still ubiquitously described as an immune attack on self. This tendency to conceptually homogenize the disease into a single entity therefore makes it possible to compare the actual *physical* experience of the disease against the *imagined* physical experience of the disease (which is shaped by language at least as much as sensation). Much of this discussion will span the second and especially third chapter, but hopefully knowledge of the basic research side of a disease like MS will add even more depth to my interpretation of personal narratives by enabling us to see the chain that leads from pipette to patient.

Recent innovations in the fields of immunology and especially molecular biology (think Dolly the cloned sheep, genetically modified crops, and stem cell research) have guaranteed that "The natural sciences have assumed a position of unparalleled authority in twentieth-century Western intellectual life" (Keller, Longino 1) and thus critiques of biomedical research methodology abound. The most well known, and comprehensive, of course, is Thomas Kuhn's *The Structure of Scientific Revolutions* - offering a historical overview of how the practice of science has evolved and changed. In the past quarter of a century there has also been a "voluminous body of published literature" linking the terms "gender" and "science"; feminist critiques of basic research methodology have been especially instrumental in the analysis of the cultural impact of science.[2] I will be referring mainly to Sue Rosser in this exegesis, but Don Marquis and Helen Bequaert Holmes also offer interesting perspectives on research ethics.[3] In particular, these critics and others offer an examination of how "culture shapes how biological scientists describe what they discover about the natural world" (Martin 103, 1996).[4] Throughout this chapter I will also be contending that culture also influences what questions scientists ask to begin with through the paradigm used. What I aim to do is offer a cultural analysis of

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[2] The recent anthology *Feminism in Twentieth-Century Science, Technology, and Medicine* (2001), edited by Creager, Lunbeck and Schiebinger, offers a particularly comprehensive overview of the impact of feminism on science.

[3] See Don Marquis, "An Ethical Problem Concerning Recent Therapeutic Research on Breast Cancer," in *Feminist Perspectives in Medical Ethics*, and Holmes', "Can Clinical Research Be Both Ethical and Scientific ?: A Commentary Inspired by Rosser and Marquis," also in same text.

[4] One of my favorite examples of how cultural ideology affects the interpretation of data is Emily Martin's "The Egg and the Sperm: How Science has Constructed a Romance Based on Stereotypical Male-Female Roles" in *Feminism and Science.* In this Martin shows how "the picture of egg and sperm drawn in popular as well as scientific accounts of reproductive biology relies on stereotypes central to our cultural definitions of male and female" (103).

the research and immune system models that lead to, and ultimately complicate, our understanding of autoimmune disease.

Because this chapter deals primarily with basic research literature, I want to begin by describing the current animal model of Multiple Sclerosis. Termed experimental autoimmune encephalomyelitis (EAE), this model requires sensitization of the immune system to spinal cord proteins that would normally be recognized as 'self,' and thus tolerated. The typical method of sensitization involves an injection of an emulsion consisting of spinal cord proteins from some creature (the donor), usually rodent, along with an adjuvant that stimulates the immune system to react against those proteins, into another creature (the host), frequently of a different species than the donor (Yao). The host creature's own immune system will now recognize both the donor's injected spinal cord proteins, as well as its own (due to sufficient similarity in protein structure), as something requiring an immune response. Within a couple of weeks there are visible signs of muscular degeneration due to immune system mediated demyelination of neural axons, beginning with a floppy tail, then hindlimb weakness, limb plegia, and eventually death (Cannella). Based on the prevailing view that "the immune system is designed to attack anything foreign while remaining tolerant of self" (Matzinger 992, 1994), this kind of model aims to mimic what we think happens in autoimmune diseases like MS by making the immune system "recognize" self as foreign.

Although animal models of disease have been around since the early days of immunology - the term "*horror autotoxicus*" was coined in 1900 by German biologist Paul Erhlich after noticing that if red blood cells from one goat were injected into another, the host goat then developed serum antibodies to the injected blood, causing it to clump and disintegrate, but injection of its own red blood cells did not, leading to the conclusion that "individual animals are unable to generate an immune response against self constituents" (Weigle 173) - they have only been in widespread use since the late 1970's. Thus, although EAE has been in the literature since the 1930's (when Rivers et al. demonstrated "that most experimental animals repeatedly injected with heterologous brain extracts over a prolonged period developed inflammatory lesions accompanied by demyelination" (Weigle 174)), more detailed examination of disease pathology and immunology has only recently been undertaken (between 1974 to 1979); the chronic relapsing EAE model and its resemblance to MS was reviewed only in 1982 by Wisniewski (Suckling).

Since then, as our knowledge of immunology has increased, along with the tools to make the study of cells and molecules possible, many variations on the basic models have appeared. Now models are chosen largely based on the kinds of questions being asked. For example, to determine the effects of recombinant human glial growth factor 2 (GGF2) on damaged myelin Cannella et al. determined to use a chronic relapsing model of EAE, rather than the acute one described above. In the chronic model donor mice are immunized with bovine myelin basic protein (MBP) along with an adjuvant that also contains *Mycobacterium tuberculosis,* to further stimulate an immune response against MBP. The lymph nodes, containing a high level of immune cells sensitized to MBP, are then removed from the donor mouse, the cells isolated and cultured in a petri dish (called *in vitro* experimentation), then reinjected into healthy genetically identical mice.

Otherwise known as 'adoptive transfer,' this technique literally transfers a disease, or symptoms, from one creature to another via immune cells, in this instance most likely CD4 T cells, that easily establish themselves in their 'new' environment and continue their task – recognition and reaction to MBP, leading to MS-like symptoms in the 'healthy' recipient.

It is interesting to note here that considering the centrality of the SNS paradigm in immunology, the fact that immune cells are readily transferred between individuals, becoming part of a different 'self,' is quite ironic. It would imply that selfhood is much more fluid than how it's portrayed in immunology. Similarly, the fact that we know the human immune system mostly through information gathered on other animal species also raises interesting questions as to the solidity of the current immune story. Even though animal models of disease are meant to give a 'rough idea' of what might be happening at the human level, the fact that similar experiments cannot be carried out in human subjects means that this data becomes instantaneous fact (until disproven by unpredictable drug reactions in human clinical trials).[5]

Returning to the importance of original research in the establishment of immunological models, the rather detailed descriptions of the two models of MS given above serve to highlight a major point about basic biomedical research – namely the high degree of manipulation and artifice involved: in the latter MS model a *mouse* was given *cow* protein in the context of *bacteria* and an *adjuvant* (with largely unknown immune

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[5] On the wall outside of the laboratory where I worked for many years was a cartoon that featured a patient lying in a hospital bed. On his chest stood an immense rat, remarking casually not to worry, "I had the same thing and they cured me!" Predictably, the patient appeared far from calmed.

stimulating properties), immune cells were then removed from the mouse and sustained *in vitro*, then injected into a different mouse. This artificially induced, yet dynamically biological system – the mouse that now has a chronic demyelinating disease – will serve as the landscape for further experimentation, usually addressing a very specific question, such as the precise function of a single molecule. The irony is that in the need to tightly control the parameters of any biomedical experiment, bits and parts (such as MBP, spinal cord proteins, lymph nodes, specific T cells) are removed from an already complex system (the donor mouse), manipulated, then re-introduced into another complex system (the recipient mouse), to create an even more complicated system, to determine the function of a single molecule, (which is often introduced into the system via a genetically engineered virus, or is itself the recombinant form of the molecule, as in the Cannella paper).

This leads to another important observation, namely that the manner in which research is conducted becomes conducive to a parts vs. whole dichotomy: the system must be disassembled, parts picked out, cleaned off, to be reassembled in such a manner that the function of specific parts can be observed. Looking at the materials and methods section of any original research paper dealing with immune system function, one will repeatedly encounter the language of exclusion and fragmentation: "Briefly, the meninges were removed and the brains dissociated using mechanical shearing and trypsin" (Stangel), "Contaminating microglial cells were removed by adherence" (Stangel), "spinal cords from the remaining 3 pairs of rats were removed rapidly and frozen" (Yao), "We find the timely development of the first oligodendrocytes….if thyroid hormone is omitted from the culture medium" (Gao), "the CNS was removed, and slices from cerebral hemispheres, cerebellum, and cervical, thoracic, and lumbar spinal cord were embedded in OCT" (Cannella), "White matter was dissected free of grey matter, meninges, ependyma and vessels, and was finely minced and enzymatically digested" (Targett) – are but a few examples.

Here, the system is not being considered *as a system per se*, but rather as the sum of all the actions of its parts. It is assumed that if a cell does something under a highly manipulated set of conditions, then it will also do the same thing when part of the larger system. In this way, the isolated cell in a sense becomes a 'self' in its own right, its genetically programmed functions a sign of free will. The potential for ascribing autonomy to cells therefore becomes immense, and so does the possibility that cellular behavior (as in, for example, autoimmune disease) will be taken as somehow reflective of an individual's morality, since the cells are still always part of a larger self. In all fairness, however, if the means were available naturally immunologists would prefer to study the system as a whole, without killing the 'host,' but at the same time such means have not been developed partly because the system, the interactions involved, are so incredibly complex that results would potentially be uninterpretable this way.

Thus, in biomedical research complexity, at least as it pertains to data interpretation, is generally to be avoided – infinite interpretive possibilities defeat the purpose of specific question-based research. Thus, the examples above of various attempts to 'remove' the complexity are also based on the need to *isolate* for observation. Certainty in the correctness of data interpretation as a primary goal is often clearly stated in research papers, again, ironically, as a justification for the excessive manipulation: "all host remyelination is suppressed by the x-irradiation and no glial cells are found in the area of demyelination so that any remyelination or cells detected in the lesion following transplantation can be attributed to the transplant" (Targett).

No where is this need to disassemble and isolate more obvious than in *in vitro* – literally meaning 'in glass' – experimentation, where specific cells are removed from a more complex system and sustained, artificial-respiration-style, in a petri dish. The description of the cell culturing process often sounds involved - "Contaminating microglial cells were removed by adherence to untreated plastic....2 x 104 cells were plated on polylysine coated 13 mm glass coverslips in 24-well plates in 0.5 ml N2B3 medium supplemented with 0.5%FCS, 62 pg/ml progesterone, 0.16 ug/ml putrescine, 50 pg/ml selenite, 4 ng/ml T3" (Stangel) - but the pink media in which the cells bathe is designed to be the *minimum* required to effectively sustain 'normal' function. In fact, the notion of minimalism can be said to be generally crucial in biomedical research – the *less* complicated the system and experimental design, the more 'true' the resulting data is thought to be. This becomes especially critical in the discussion section of any research paper, where relevance to the 'natural' system must be demonstrated, and where it becomes easy for competitors and critics to discount the data based either on excessive manipulation and complexity, or on excessive minimalism; implicit is the understanding of an ideal placement of experimental design somewhere along the uninterpretably complex-overly simplistic spectrum – the problem is that no one can definitively state exactly where that is.

Attempts to reconcile experimental minimalism with the inherent complexity of the biological system under investigation often lead to the tentative, hypothetical re-introduction of single parameters in the discussion. If the desired result is not achieved, the temptation will always be to blame it on the absence of a specific parameter that was removed for the sake of interpretive simplicity. Again, what is apparent here is the incredible flexibility of the immune system - the cells can and *do* function under a multitude of different conditions. Consequently, a common feature of many original research papers is the insecure, questioning language that is used when finally discussing the relevance of the data to the natural situation, as witnessed by Targett's paper where transplanted glial cells (obtained from the human brain) failed to remyelinate rat axons: "the lack of myelin sheath formation raises the following questions: i) are mature oligodendrocytes able to myelinate axons?; ii) is the lack of myelin sheath formation a consequence of the xenogeneic situation?; iii) can the failure of remyelination be related to sub-optimal conditions within the lesion associated with the absence of astrocytes in the lesion?"

Conversely, researchers can also blame the data on the *presence* of specific experimental factors, and propose that in their absence the data would better fulfill preconceived expectations. For example, in their paper on cell-intrinsic timers, Gao et al. question the effect of a single substance named forskolin on the behavior of oligodendrocytes in culture: "We add forskolin to our purified cell cultures because it greatly improves cell survival at clonal density, but it is not known if this activates or mimics a signaling pathway that is normally activated in oligodendrocytes lineage cells *in* *vivo*." In this way there is the brief acknowledgment of the incredible flexibility of the data. The data itself is always 'correct' in that it reflects what happens under a specific set of conditions, but since manipulation of experimental conditions can yield very different results, the question always remains – is this what truly happens in the *natural* system? The issue is certainly not helped by the fact that one can usually show the desired result by choosing the 'appropriate' model in which to test a hypothesis. In the above example Gao et al. show results counter to those of another research group, but then remark that when cell culture conditions were made the same, with the addition of forskolin, that the results were suddenly in sync: "When Ibarrola et al. added….forskolin to their cultures, as we do,….their results were more similar to ours. It remains to be seen which conditions most closely resembles those *in vivo*."

The cautionary note at the end, as to the relevance of the data to the 'real' situation, is a common one to make and actually quite ironic, since the real situation is technically unobservable in its undisturbed state by current scientific means. As we have seen, the gathering of data usually entails removal of tissues and cells from the host, and invariably the death of the host, to generate (ideally, for the purposes of statistics) numbers. What the majority of data represent is therefore only a snapshot of a very dynamic, complex system. And in order for the data to be of ultimate use, the researcher must then extrapolate that single data point both into the biological past and future, imagining what would have happened prior to, and what is most likely to happen after this particular snapshot.

In a similar way, the practice of medicine also operates based on snapshots: the diagnosis is based largely on numbers (white blood cell levels, enzyme levels, blood pressure, etc) that represent (very poorly) one discreet moment in the body's existence. Yet based on that one snapshot there ensues a retroactive examination of the body - what led to this? And a prognosis - how is this most likely to progress and affect my life? Since components of the immune system appear able to bear infinite manipulation, then experimental possibilities are also limitless, which means that knowledge acquisition is limited and dictated by the kinds of questions researchers ask; if you can think of the question, chances are you can come up with the experiment which will give you the answer you desire. And what dictates the questions asked is ultimately the paradigm under which the researcher is operating.

Despite collective agreement that the true complexity of a biological system remains highly elusive, the highly results-driven - and now profit-driven[6] - nature of biomedical experimentation still demands conclusions. Thus, in the discussion section of most research papers one can find firm statements as to the centrality of the molecule under investigation to the system as a whole: "Our finding that most E18 precursor cells stop dividing and differentiate within 1-3 days when thyroid hormone is added....suggest that thyroid hormone acts directly on the embryonic precursor cells" (Gao), "Our results strongly suggest that direct receptor-mediated effects of IGF-I on oligodendrocytes

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[6] See Huag, Marie and Bebe Lavin. *Consumerism in Medicine: Challenging Physician Authority.* Beverly Hills: Sage Publications, 1983; Oldenziel, Ruth. "Man the Maker, Woman the Consumer: The Consumption Junction Revisited." *Feminism in Twentieth-Century Science, Technology, and Medicine.* Ed. by Creager, Lunbeck, Schiebinger. Chicago: The University of Chicago Press, 2001; and Robinson, Jeffrey. *Prescription Games: Money, Ego, and Power inside the Global Pharmaceutical Industry.* Toronto: McClelland and Stewart, 2001.

helped reduce demyelination and promote myelin regeneration" (Yao). On some level a single cell or molecule will be critical to how the whole system functions, but what seems to be repeatedly forgotten is that just because something can function in a minimalist environment, does not mean that it is also not capable of responding to the multitude of other factors that have been omitted (or even remain undiscovered). There is a great difference between claiming that in a particular experimental system some parameter affects the behavior of a cell or molecule, versus claiming that that parameter alone affects the behavior of the cell in only one fashion always. In the paper by Gao et al. quoted above, they discard the possibility that numerous factors may affect the differentiation of embryonic precursor cells, in favor of "a simpler model, in which a single thyroid-hormone-regulated timer controls normal oligodendrocyte development" (64). Correctness of data interpretation aside, what this demonstrates is the desire for simple answers, for one cause. And although trying on the simplest answer first is a common guiding principle in most sciences, when applied to the field of medicine it can easily lead to self-blame on the part of the patient (in the form of statements such as, "It must have been the stress," for example), and mental rejection of the culprit - like a certain kind of cell - from the body, labeling it as foreign.

Interestingly, this minimalist approach to biomedical research does in actuality also translate to human therapeutics. Or perhaps more accurately, the pharmaceutical industry (which now funds a large portion of basic research) further encourages original research towards this oversimplification and subsequent fragmentation of the immune system - complicated drugs consisting of multiple immunomodulating molecules are much less attractive than a single cytokine tonic. The current treatment of choice for MS, for example, involves the systemic administration of the recombinant form of a naturally occurring cytokine called Interferon-Beta (IFN-β) (Zhang). The efficacy of this single molecule in modulating symptoms is largely undisputed, yet "despite tremendous efforts the mode of action of IFN-β in MS patients is still unknown, and it has proven difficult to correlate many of the suggested mechanisms with the in vivo effects of this cytokine" (Teige). Thus, by fragmenting a complex system, by asking the kinds of questions that demand a single answer (or molecule), biomedical research yield single culprits.[7] But when this single variable is re-introduced into another complex system (the patient), that cannot ethically and legally be fragmented again (like a mouse can), the 'data' is once again uninterpretable. This is also an interesting reversal of the scientific process, where the therapy is being used as a tool to study disease pathology, rather than emerging as a final result of the fact gathering process: "Recognition of how these agents work to regulate the immune system may lead to a better understanding of disease mechanisms, as well as the development of more effective therapies" (Zhang).

Examples of this type of research protocol (where the preliminary fact gathering process leads to the development of a product that is used as a tool for further fact gathering that then leads to the development of even 'better' therapies) are plentiful. This is especially true in the field of autoimmune disease where the 'fault' is perceived as

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[7] Some other recent titles in the scientific literature that also promote a single molecule as 'culprit' and possible target of therapy: Singh, R.R. "IL-4 and many roads to lupuslike autoimmunity." *Clin Immunol.* 2003 Aug; 108(2):73-9; Scheinin, T. "Validation of the interleukin-10 knockout mouse model of colitis: antitumour necrosis factor-antibodies suppress the progression of colitis." *Clin Exp Immunol.* 2003 Jul; 133(1):38-43; Chen, C.R. "The thyrotropin receptor autoantigen in Graves disease is the culprit as well as the victim." *J Clin Invest.* 2003 Jun; 111(12):1897-904.

endogenous, meaning that it is some component of the host's own immune system that is perceived as the culprit, but the mechanisms of disease etiology remain largely unknown. Hence, the patient becomes the guinea pig, where 'experimental conditions' are manipulated through the prescription of various immunomodulating drugs (like the IFN-β described above) in order to study the immune reaction. The patient in a sense becomes the petri dish full of cells to which various compounds are added (recombinant cytokines), or taken away (antibodies that effectively block the function of a given, naturally occurring, molecule).

A possible effect of this kind of experimentation on a patient's sense of self might be that the disease, and any experience associated with the disease, is viewed as a separate kind of reality, a false reality; if the molecules, the cells, and hence the disease itself, can simply be removed, leaving an intact healthy being behind, then the disease is not a legitimate aspect of the life being lived. The central question here, probably too grand to ever be effectively answered, is what constitutes a functional being? On the physical level, how much can be removed before the being is no longer 'whole'? And conversely, does the addition of things like synthetic antibodies or cytokines, or an infection of any sort for that matter, conceptually make a being more whole?

Although biomedical research is certainly not alone as a scientific discipline in its tendency to fragment and oversimplify a complex system into manageable pieces, especially once such an overwhelming amount of data has been collectively amassed, it is unique, however, in how the eventual articulation of how the system works can affect the personal conception of self in such an intimate way. At some point the individual pieces of data, the papers that finger this or that molecule or cell as responsible for disease pathology, must be assembled into a more complete narrative. Since this narrative involves descriptions of cellular behavior in the context of other cells and tissues, and since science has a marked tendency to explain the world based on the current social, political and economic ideas about the world, the body story that emerges will be based as much on ideology as on gathered data. And the way that ideology usually emerges is through the paradigm that one uses.

The centrality of paradigms in biomedical research becomes especially apparent when there is an attempt to assemble all of the various specialized findings into a coherent story – otherwise known as a review article. The significance of the all the original research articles dealing with remyelination quoted thus far is that they are all featured (along with over 120 such others) in the review article "Why Does Remyelination Fail in Multiple Sclerosis," by Robin J. M. Franklin (2002). In this review article Franklin attempts to assemble whatever pieces of the 'remyelination puzzle' are currently available. There is nothing extraordinary about this article, (other than that it appears in a very prominent scientific journal, *Nature Reviews Neuroscience*, and that it covers over 130 original articles); it is being used here mainly as a model of how the body story becomes constructed.

To clarify, the term 'model' is being used to denote a workable set of rules or schema describing a process. In immunology models usually operate in linear time with a limited set of variables and are meant to inspire a mental image of the immune system in action. The term 'paradigm,' by contrast, "discloses a set of recurrent and quasistandard illustrations of various theories in their conceptual, observational, and instrumental applications" (Kuhn 43). Another way of understanding the distinction, is that the model proposes a 'fit' for how all of the individual pieces of data relate, allowing for interpolation and extrapolation, while the paradigm governs in a nebulous way the conceptual framework in which the models are developed - an "implicit body of intertwined theoretical and methodological belief [and I would also say *ideological*] that permits selection, evaluation, and criticism" (Kuhn 17).

Thus, a paradigm is the collective conceptual understanding of 'reality' for a specific group of individuals. I inserted the term 'ideology' as part of the beliefs that permit "selection, evaluation, and criticism" precisely because selection and evaluation of information entails value judgment. Again, the data is always correct in that it relates (in a highly limited way) what happens under a specific set of experimental conditions, therefore how can it be wrong and thus excluded? Inclusion and exclusion of data will therefore be based on whether the data further validate a given paradigm. For example, since many immunological paradigms impose hierarchy on cells resembling societal hierarchies based on gender, race, class, then data that challenge these hierarchies may be excluded from the final narrative. In chapter two I relate how feminized B cells are said to require 'help' from masculinized T cells; although Lafferty and Cunningham proposed in 1974 that T cells also require 'help' from another cell type (the antigen presenting cell), the finding was all but ignored for the next 13 years in favor of Bretscher, Langman, and Cohn's 'helper T cell in control' model (Matzinger 5, 2001). What makes this especially relevant in biomedical research, and ultimately of most importance to the patient and the care-giving community, is that once a dominant paradigm is established it limits and guides the problems to be solved, the therapies developed, but also the version of the body story proposed to patients by medical experts, and even the nature of the patient-expert interaction itself (which, as I will discuss in chapter two, can be mirrored on cellular interactions).

At a recent talk delivered at the immunology rounds at McMaster University, a member of the audience meant to remark, "I'll believe it when I see it" to an observation made by the speaker. Instead, the phrase was interestingly reversed to: "I'll see it when I believe it." At this historical moment the latter version of the phrase is probably the more accurate description of the field; even though individual researchers concentrate on specific pieces of the puzzle, there is still a collective preconception of what the final picture should look like. Thus, in a review article like Franklin's it is partly a priori assumptions, value judgments, the fit of the data to the operating paradigm, and the fit of the individual papers to each other (largely dictated by the rarely acknowledged but shared adherence to the same paradigm) that dictate the inclusion criteria. Interestingly, even with shared adherence to a collective paradigm, the specificity of the individual data to a particular (highly manipulated) experimental system still makes assembly difficult. The review author's voice is strong when simply relating the findings, but much less so when finally proposing a coherent model: "At present, it is not possible to provide a comprehensive explanation of why remyelination fails in MS. This is, in part, because we do not fully comprehend how remyelination occurs" (Franklin).

Often there is also the acknowledgement of the inadequacy of a linear causation model in explaining the sophisticated complexity of the 'natural' situation: "a hypothesis can be proposed for remyelination failure in which the signalling environment becomes inappropriately regulated, or 'dysregulated.' According to this hypothesis, there are no individual villains of the piece that are responsible for remyelination failure. Instead, the process fails because the complex and finely tuned mechanism by which it proceeds loses its precise coordination" (Franklin). The vagueness of such statements is particularly ironic considering that the majority of a review article poses as a finger-pointing exercise: "There is likely to be considerable redundancy in the system, with the presence of some factors being compensated for by the presence of others. However, some factors might be non-redundant, and their presence or absence might determine the efficacy of remyelination" (Franklin).

The contradictory nature of Franklin's paper (and of most immunological reviews) is further exemplified when under the heading "Finding the solution" the paper states: "Given the complexity of the signalling environment that is required for remyelination, it is unlikely that the absence or inappropriate presence of single factors will provide a full explanation." Because at the moment we only know the immune system as its bits and parts - as Jonathan Mann, a Harvard researcher, remarked at the 1992 Amsterdam AIDS conference: "We are all working on the twigs, the leaves, the branches, but no one sees the forest" (Martin 129, 1991) - 'finding the solution' becomes an exercise in bias: the puzzle pieces, since the final image is unknown, are therefore made to fit into an agreed upon image. But since all immunologists have are the bits and parts, there is also constant tension (oscillation) between excitement at the possibility that some newly discovered molecule or cell will solve (or unite) the entire puzzle, and the acknowledgment of the infinite complexity we are surely not grasping. The conclusions that emerge from a 'parts-centered' paradigm *by definition* will not faithfully represent the 'natural' system because the system is not merely the sum of its parts. I agree with Thomas Womack, an M.D. specializing in holistic medicine, that "there's more to a tomato, as an example, than just the individual parts. There's a whole integrated function. And I think the immune system is like that" (Martin 86, 1991).

If one accepts the view that our social reality greatly influences the construction of 'scientific reality' - through the kind of paradigm used to framework all subsequent experimentation and data interpretation - then the self-nonself immunological paradigm[8] can be said to directly reflect many of our society's cherished views and values. Since Burnet proposed in 1959 that B cells carry receptors that recognize foreign antigens, "immunologists have based their thoughts, experiments, and clinical treatments on the idea that the immune system functions by making a distinction between self and nonself" (Matzinger 301, 2002). Based on the (very practical) assumption that the immune system "must make some distinctions so that it can eliminate pathogens without destroying the body's own tissues in the process" (Matzinger 4, 2001), the SNS paradigm assumes that it is 'foreignness' that initiates an immune response. Crucial to this theory is Lederberg's proposal that immune cells that react against self are deleted early in their development.

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[8] Many immunologists still refer to it as a 'model,' but it has long ago moved from being just a model, to immunological gospel. As Tauber notes: "By the 1970s, CST [clonal selection theory] had become dogma and 'self' was a prominent member of immunology's vocabulary" (Tauber 242, 2000).

When it was discovered by Bretscher and Cohn (1969) that B cells hypermutate their receptors upon encountering their specific pathogen, "thus allowing the possibility that new, autoreactive specificities could appear and lead to unstoppable autoimmunity" (Matzinger 5, 2001), the model morphed again to accommodate this finding (see figure 1). Now B cells required 'help,' or rescuing "by the receipt of timely and appropriate help from a helper cell [a kind of T cell]" (Matzinger 5, 2001), to be able to react against pathogens. Resembling the heroic rescue of the damsel in distress by the masculine hero of so many comics, books, and movies, this explanation of events clearly demonstrates the socially biased nature of science.

Another - equally biased - way of describing this immunological event, highly reminiscent of traditional western male-female relations, is that B cells need permission from T cells to do anything. To support this view researchers found that T helper cells do indeed interact with B cells that have found their specific pathogen and deliver signals (through released cytokines) that appear to 'rescue' B cells from the death that would otherwise occur in the absence of these signals. This particular version of the model lasted until 1974, when Lafferty and Cunningham asked whether the T cells also require some sort of signal from another cell to become fully functional (Matzinger 5, 2001). And of course, it was found that T cells do interact with a cell now known as an antigen-presenting cell (APC). Except in this instance it is said that "T cells need a *costimulatory* signal," (Matzinger 5, 2001) rather than 'help' or 'rescue' per se - a word like costimulation implying a mutually beneficial interaction between equals. But this version of the model was for the most part ignored until 1987 when Jenkins and Schwartz found that APCs rendered immobile by gluteraldehyde fixation were incapable of interacting with T cells (Matzinger 6, 2001). Unable to ignore this compelling data, the scientific community began looking for, and not surprisingly found, a plethora of said 'costimulatory' molecules on APC's.

The more interesting question, however, is "Why had it taken so long? Why had the T helpers and their signals been applauded and carefully studied while the costimulatory signals of APC's remained ignored?" (Matzinger 6, 2001). Polly Matzinger's answer is that "costimulation did not fit into a self-nonself model" (6, 2001), in that APC's do not distinguish between self and nonself; they can pick up anything. But the notion of an immune system not solely obsessed with the recognition and elimination of foreignness "made people uncomfortable" (Matzinger 6, 2001). I would add here that the idea of cells anthropomorphized as masculine needing help or rescue also makes the mostly male scientific community 'uncomfortable.' Predictably, in 1989 Charlie Janeway (also the co-author of the most widely studied undergraduate immunology textbook) "found an ingenious way to meld costimulation with self-nonself discrimination" (Matzinger 6, 2001). Janeway proposed that APCs are genetically programmed, through the receptors they use to interact with pathogens, to recognize evolutionarily distant organisms like bacteria. And voilà! Our idea of the world, a world where the foreign is to be attacked and eliminated, the feminine is subservient to the masculine, and the important interactions are those between males, is thus conserved and perpetuated.

What that rather extensive historical overview was meant to convey is how the operating paradigm can influence scientific inquiry, and also how social ideology (referring to the ideas and objectives that influence political and social procedure for a given group or culture) significantly contributes towards the initial construction of that paradigm, which is then used to validate that same ideology - therefore these systems are *mutually* reinforcing rather than unidirectional. In "The Egg and the sperm: How Science has Constructed a Romance Based on Stereotypical Male-Female Roles," Martin notes how "the social ideas of Malthus about how to avoid the natural increase of the poor inspired Darwin's *Origin of Species*. Once the *Origin* stood as a description of the natural world, complete with competition and market struggles, it could be reimported into the social order of the time" (113). Similarly in immunology, paradigms are constructed based on already naturalized notions of proper social interactions, values, and beliefs, and then data is interpreted in such a manner as to reassert the naturalness of those same values and beliefs. At every point along the construction of the SNS paradigm the questions asked and data generated were made to further validate the paradigm. The fact that all of the cells discussed (and this includes the pathogen) were found to interact with, and critically depend on, other immune cells, could have been used to support the view that extensive communications networks are necessary in such a complex system, and that nothing will happen if interactions *between all the cells* are not coordinated - hence the notion of an immune *system*.

Again, all of the versions of the SNS model discussed above are just snapshots of moments. What happens after the bacteria engage the APCs? The APCs interact with T cells, which interact with B cells (which have already interacted with the same bacterium), which then release antibodies that coat the bacterium (which has already been coated with complement - a normal component of plasma that aids the binding of antibodies) so that it can more effectively be taken up by phagocytes like neutrophils and macrophages which have interacted with chemokines and epithelial cells in order to find the site of infection, etc., etc. (Janeway). This very simplified, but still dizzying, account of an immune process demonstrates the complex interrelatedness of the system: "The immune system integrates these signals at the cellular level and continuously updates its activities. The immune system is a *reactive system,* just like a dialogue" (Tauber 217, 2000). If we saw the immune system in action, in real time, it would look like a giant, indecipherable mess. So why has the scientific community chosen to articulate it this way? Why is the B cell said to require rescue and help, and the T cell costimulation, rather than both simply needing to interact with many other cells in order to coordinate the immune response? And why does it seem like these required interactions are some sort of failing on the part of the cells, that every time the model is found too simplistic and another cell or molecule has to be added to the equation there is such gnashing of teeth among the immunology community? Again, the answers to these questions reside in the fact that social reality helps construct scientific reality. And our current social reality is not conducive to conceptualizing an immune reality based on extensive communication, interdependence (vs individualism), and egalitarian interactions.

So if models and paradigms of immune function are mainly *instrumental*, rather than actually representing 'reality,' what would happen if some of the main assumptions - like the notion that the primary function of the immune system is to recognize self from nonself, for example - were rejected? Recognizing that although the SNS paradigm has been useful in propelling research forward, but that even after 50 years of fine-tuning is still unable to explain many observations, (such as how "organisms go through puberty, metamorphosis, pregnancy, and aging without attacking newly changed tissues," and "why most of us harbor autoreactive lymphocytes without any sign of autoimmune disease, while a few individuals succumb"(Matzinger 301, 2002)), Polly Matzinger proposes instead that "an evolutionarily useful immune system should concentrate on those things that are dangerous, rather than those that are simply foreign" (4, 2001).[9]

Reiterating that the SNS model (and *any* model of the immune system) is simply that, a complex but ultimately cartoon-like representation of what immunologists *think* is happening used to frame current data and inspire future experiments, Matzinger places the SNS model under scrutiny as an *instrument* of science, enabling her to then critique and reject some of its major tenets. One of the main compelling reasons for the rejection of the terms 'self' and 'nonself,' that she gives, is that in the forty years of usage (in the immune context) scientists have been unable to agree on precise definitions: "each model has a different definition of 'self,' ranging from: (1) anything persistently present from the moment the immune system develops; (2) anything persistently present at a high enough concentration; (3) anything present in the thymus; (4) anything present in the thymus and/or present at a high enough concentration and for long enough in the secondary

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[9] In "The Elusive Immune Self: A Case of Category Errors" Tauber outlines how these 'context-based models of immunity' in fact began (formally) in 1974 with Niels Jerne's idiotypic network theory. Briefly, the theory "proposed that antibodies formed a highly complex interwoven system, where the various specificities 'referred' to each other" (466). One of the radical implications of the theory was that "There is no 'self' and 'other' for the immune system" - "foreignness per se does not exist in this formulation" (466). Rather, an immune response is initiated when there is a perturbation of the system through antibody reaction with some substance. For the purposes of this thesis, however, I will be focusing mainly on Matzinger's model.

lymphoid organs all else being ignored; and (5) anything part of the immunological homunculus"[10] (Matzinger 7, 2001).

The term 'nonself' is as equally problematic since it implies not only foreignness, but also "something that elicits an immune response," making foreign pathogens that do not elicit an immune response neither self nor other (Matzinger 8, 2001). According to Matzinger, "Antigens associated with danger should be dealt with, and those that are not should be tolerated" (8, 2001). This slightly altered viewpoint also allows for self that "need not be ignored" and nonself that "need not always be attacked," as well as allowing "the boundaries of self to change as the body changes, matures, procreates and grows old" (Matzinger 8, 2001). The seminal importance of this latter point to the experience of an illness like MS will become apparent shortly. Termed the Danger Model, this "small step that lands us in a different point of view" (Matzinger 6, 2001) is much more than simply an alternate model of the immune system - it is a radical subversion of the ideology that has led to the prominence of the SNS paradigm.[11]

Briefly, "The Danger model is based on the idea that the ultimate controlling signals are endogenous, not exogenous. They are the alarm signals that emanate from stressed or injured tissues" (Matzinger 7, 2001). Prior to this tissue cells were seen as passive entities to be invaded by foreign pathogens or protected by the immune army, rather than active participants in the immune response (similar to how medicine has historically treated female patients, as will be discussed in the third chapter). Instead,

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[10] The term was originally coined by Cohen and refers to the *natural* regulation of autoimmunity in healthy individuals, since every body is populated with autoantibodies and autoimmune T cells (Cohen 216).

[11] For the first, rather comprehensive, articulation of the Danger Model see Matzinger, P. "Tolerance, Danger, and the Extended Family." *Annu. Rev. Immunol.* 1994; 12: 991-1045.

Matzinger posits "that the activation state of an APC depends on the health of the cells in its neighbourhood" (7, 2001), and that rather than being tailored to the nature of the pathogen, the immune response "is tailored to the tissue in which the response occurs" (Matzinger 304, 2002). Significantly, once the question was posed and researchers began looking, it was indeed found that cells emit molecules that classify as 'danger signals' (Brown and Lillicrap 2002; Moseley 2000). The DM does conserve all of the elements also present in the SNS model: the B cell still interacts with the T helper cell in the depicted fashion, which still interacts with the APC, which still interacts with the pathogen (Matzinger 7, 2001). The difference, however, is that Matzinger brings tissue cells "into the conversation," as well as acknowledges that "Semantics,or the study of meaning, is critically important to any conceptual or theoretical discussion" (Matzinger 7, 2001). Thus, the emphasis, and the *language* used to represent the immune system's workings, shifts from hierarchy to the importance of all the interactions between cells *and* their environment.

Replying to the criticism that it is "merely" an issue of semantics, Matzinger responds: "The answer is that some of the differences are semantics, but I would remove the term 'merely'"(7, 2001). This sensitivity towards the crucial role of language itself in original research - largely dictating the questions asked, experiments performed, and thus the version of body story constructed - is what prompts the motto: "immunity is a conversation not a war." Rather than studying immunity "from the point of view of various forms of SNSD models in which immunity is controlled by the adaptive immune system, an army of lymphocytes patrolling the body for any kind of foreign invader"

(Matzinger 8, 2001), the DM portrays the body instead as an open and diverse "habitat" - "welcoming the presence of useful commensal organisms and allowing the passage of harmless opportunistic ones" (Matzinger 8, 2001). Urging for an end to this "cold war with our environment," this alteration in point of view from the body as isolated and highly defensive, to welcoming but observant, allows for the conceptual construction of a body "in harmony with our external and internal environments" (Matzinger 8, 2001). And with this kind of paradigm in place not only do we greatly expand research and therapeutic potential by asking novel questions, but the mental conception of our physical existence is altered in such a way that disease (especially autoimmune disease) becomes much less about bodily (and possibly moral)[12] inadequacy, and more about change, adaptability, and outcomes of highly complex cellular interactions.

Finally, I want to stress that I am not claiming that the DM is a more accurate version of immunity. As Tauber notes: "it is apparent that none of the respective models are 'wrong' in any conventional sense. Their 'rightness' derives from their respective abilities to offer comprehensive and coherent explanation of current data, and to provide interesting proposals for future research" (241, 2000). It is simply an alternate version, one that may alleviate some of the social stigma associated with an autoimmune disease like MS, but also be able to portray the body and disease in a manner more in tune with

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[12] In *Illness As Metaphor* Sontag remarks how "Any disease that is treated as a mystery [referring specifically to tuberculosis and now cancer] and acutely enough feared will be felt to be morally, if not literally, contagious" (6). Often the mere *name* of a disease like TB, cancer, and now AIDS, because of the moral accusation they imply, can fill the patient with dread; "As long as a particular disease is treated as an evil, invincible predator, not just a disease" most people "will indeed be demoralized" (Sontag 7) by the diagnosis, irrespective of the actual bodily symptoms.

the experience of the dis-eased body itself, thus possibly mitigating the crisis in patient identity often resulting from the current understanding of the disease.

The model itself is far from perfect (as Matzinger herself freely admits), and it will similarly shape the kinds of questions asked and answers found, but at least it does not hinge on the Cold War notion that the body itself, and thus the individual, is an isolated fortress and that foreignness is always malicious and must be destroyed. As the second chapter will demonstrate, such versions of immunity are based as much on the political, economic, and social context as on actual scientific data.

Again, the aim of this first chapter was to introduce the reader to the notion that immunology is far from a strictly objective science, and that even on the level of original research - which always claims to be politically and socially detached - one can see the operation of pre-existing discursive constructs. Since most critiques of immunology focus primarily on the wider philosophical implications of the models and paradigms used, I wanted to take another step back and show how even the research methodology used shares in these wider implications.

However, because the systems that construct our realities are so intertwined, if culture can influence science, then perhaps science can also influence culture. The significance of Matzinger's DM to this discussion is precisely that it has the potential to alter not only how we do science, but how we conceptualize our bodies and illness, and how we interact with each other and nature. Ironically, it is in contemporary research methodology itself that the self-nonself paradigm falls apart in favor of the DM: in primary research we are consistently faced with an immune system that appears infinitely malleable and adaptable to circumstance, rather than based on rigid rules of continuous self-affirmation and protection. The self of immunity, as increasingly complex and artificial experimental conditions show, is a fluid non-entity that easily adapts to a perpetually changing context. Indeed, as the next two chapters will demonstrate, illness is not merely a personal, individual experience of the body reacting to infection, itself, or perceived danger, but a very social experience; the patient, like any individual cell, functions within the context of the larger whole, whether that be the society at large, the care-giving community, or one's closest relations. In a sense, everyone must mentally grapple with illness, whether technically healthy or ill, because illness belongs to the realm of language. Thus, the way illness - especially something as baffling and complex as autoimmune disease - is articulated by researchers, and subsequently by medical practitioners, will influence more than just how the immune system is imagined, but also how social structures are imagined.

Chapter Two: Reading the Language of Immunity

> O Aristotle! If you had the advantage of being "the freshest modern," instead of the greatest ancient, would you not have mingled your praise of metaphorical speech, as a sign of high intelligence, with a lamentation that intelligence so rarely shows itself in speech without metaphor - that we can so seldom declare what a thing is, except by saying it is something else?
>
> George Eliot, *The Mill on the Floss*

In this chapter I will examine how immunology as a system of knowledge has been shaped by, and continues to support, various cultural institutions. The self-nonself immunological paradigm that makes autoimmunity so conceptually problematic was formulated within a certain sociopolitical and economic context, rather than having simply emerged from gathered data, and I will attempt to demonstrate how the two serve mutually to reinforce each other. The precedent for this kind of analysis has been well set by critics like Haraway, Martin, Sontag, Stacey, and Taussig - who states that "by denying the human relations embodied in symptoms, signs, and therapy, we not only mystify them but we also reproduce a political ideology in the guise of a science of (apparently) 'real things' - biological and physical thinghood" (84). What I am offering is a cultural analysis of autoimmune disease more specifically and the immunological paradigms in which the disease is understood - which I will relate back to social ideology. As in the first chapter, the crucial theme here is context. To a certain extent the contemporary sociopolitical economic climate is sufficiently different from the one in which immune system discourse (as we now understand it) was originally conceived in the mid-twentieth-century. Thus, novel, context-based versions of the immune system (such as the Danger Model) may be a better 'fit' for the postmodern experience of illness.

This is especially true in the case of autoimmune disease, which traditional models of immunity have difficulty accommodating. This chapter also serves to frame the personal narratives of AID discussed in the final chapter in a specific cultural context.

I want to begin by outlining how technology is currently practiced in Western societies, drawing primarily on Ursula Franklin's critique of *The Real World of Technology*, originally delivered as six public talks as part of the CBC's annual Massey Lectures series in 1989. Although this may seem like a strange place to start, I want to establish, in a more general sense first, how we as a society *work* (literally), and especially how the nature of our work shapes the way we relate to one another. With two different models of technological practice in mind (holistic versus prescriptive), I will then turn to the language of immunology, demonstrating how the way the *immune system* works (or how the individual cells 'do their job') reflects the manner in which we as a *society* practice technology. This relationship is of course quite fluid, as Matzinger notes: "I believe that we should choose our models carefully because the way we *think* has enormous influence on what we *do*" (8, 2001, emphasis mine). Especially important to this part of the discussion is the role of military terminology and analogy in the immune system and in society, drawing economics into the conversation.

Next, I want to anchor the discussion of work (as inspiring certain kinds of relations between those who practice it) in 'the real world of biomedicine,' demonstrating with a specific example how the largely prescriptive nature of medicine affects the patient-expert interaction - which will be expanded upon with examples from personal narratives of autoimmunity in the third chapter. And finally, I will examine how the

Danger Model in particular relates to the sociopolitical systems that govern our interactions, possibly pointing the way towards a different approach to the practice of immunology, one less conducive to the fragmentation of the field, the immune system, the body, and ultimately identity.

In the first lecture of the series Franklin begins by observing how "Technology is not the sum of the artifacts, of the wheels and gears, of the rails and electronic transmitters," but rather a system of knowledge that "involves organization, procedures, symbols, new words, equations, and most of all, a mindset" (Franklin 12). Similarly, advances in immunology, such as the development and use of immunotherapy, also arise from, and contribute towards, a certain system of knowledge and practice, or mindset. Rephrased slightly, this means that medicine is not merely the sum of all the needles and secret elixirs, the IFN-β1 injected into MS patients, but is also constructed by - even as it helps to construct - a complex socioeconomic political *system*. As Michael Taussig notes in "Reification and the Consciousness of the Patient" in *The Nervous System*: "things such as the signs and symptoms of disease, as much as the technology of healing, are not 'things-in-themselves,' are *not only* biological and physical, but *are also* signs of social relations disguised as natural things, concealing their roots in human reciprocity" (83). In this way Taussig argues, as I will, that all of the 'things' that make up our reality, and that we tend to conceptually autonomize as discrete entities onto themselves, are in fact reflections of, and justifications for, the social order.

Looking at technology as practice, "what is actually happening on the level of work" (18), Franklin defines two different forms of technology based on "distinctly different specializations and divisions of labour" (18) - what she terms *holistic* and *prescriptive technologies* (18). The emphasis here is primarily on *how* things are being done. Typically then, holistic technologies are those normally associated with the execution of a craft, where the artisans "control the process of their own work from beginning to finish" (18). This entails situational decisions made in the process of work that draw on experience towards the solving of novel problems should they arise (18). Each product is therefore unique in some way. It is important to stress here that both kinds of technologies are being defined by the different kinds of human interactions involved in the completion of the product. Although direct participation at every single step of the process is not necessarily a requirement of holistic technologies, there is also rarely "the kind of organization where one woman characteristically specializes in gathering the clay, another in fashioning it, and a third in firing the pots" (Franklin 19); holistic technology, by definition, entails a doer "in total control of the process" (19).

In sharp contrast, prescriptive technologies entail "specialization by process," where "the making or doing of something is broken down into clearly identifiable steps. Each step is carried out by a separate worker, or group of workers, who need to be familiar only with the skills of performing that one step" (Franklin 20). This is what is classically meant by the term 'division of labour' (20). The perfect example is that of the modern sewing factory, or sweatshop, where the garments are produced "by the prescriptive technologies that created a situation in which one seamstress only sewed up sleeves, another worker put them in, another made buttonholes, another pressed the shirts" (Franklin 101). But as the complexity of the technology increases, so does the demand for expertise in very specific narrow areas of the practice, leading to the fragmentation of the workplace. The cost of this highly specialized knowledge is the loss of breadth of knowledge, the workers now largely ignorant not only of each other's areas of expertise but also of the precise functioning of the whole. This increased fragmentation subsequently leads to even more complex infrastructure with multiple hierarchical levels of management and thus the loss of power for the worker (Franklin 100).

It is evident that the dominant system in place ever since the industrial revolution has been one that favors the prescriptive technological model. One of the things the first chapter emphasizes is how complex the field of immunology has become, both in the knowledge acquired and tools used. An individual researcher may now spend their entire academic career exploring the function of a single cytokine. And often for the principal investigator this 'exploration' is reduced to manuscript preparation and grant proposals, where various technicians and students actually carry out the experiments. When it comes to the experiments themselves, it has also become customary that tasks are assigned to different personnel, depending on their expertise. In this way immunology has truly become a prescriptive technology. And if the manner in which research is done affects the kinds of models proposed (referring to models of immunity based on the SNS paradigm), then it is not too difficult to see how the fragmentation of the immune system into bits and parts and strict hierarchies reflects the prescriptive nature of the field. Again, the interesting contradiction, though, is that infinite fragmentation of the immune system into its parts is actually supportive of contextual models of immunity like the DM, where roles are more fluid.

Although one can argue that this sort of fragmentation based on highly specialized tasks is somewhat inevitable in a field as vast and complex as biomedicine, what it also does is severely limit the range of possible action of any one component of the system - in this case individuals themselves. Put another way, prescriptive technologies demand that individuals adhere strictly to their (usually narrow) prescribed roles. And since the patient is part of the system their role is no less rigid than the expert's - neither is allowed to deviate. Thus, I am positing patienthood as a role played by an individual who has decided to seek medical attention for their disease. The extent to which the patient, once having inserted themselves into the system, can choose the parameters of this role is highly debatable. For example, imagine medicine as an automobile factory where hundreds of individuals have their prescribed task. Within this factory the patient is just one of the workers (let's just say the one who puts on the doors). If the patient is to become 'well' and leave the factory, then the next individual to be assigned that specific job must perform the same task in exactly the same way as the previous worker or the system falls apart, since all of the other roles have already been assigned. Compartmentalization of the person "into the status of patienthood" then allows the reification of the patient "into the status of thinghood as opposed to that of a mutually interacting partner in an exchange" (Taussig 100). The patient role is further complicated, however, by the fact that the whole system supposedly exists for their well being - thus the patient is simultaneously a worker in the factory and in a sense the product being assembled.[13] In this way patient compliance, in terms of complete surrender of their reified body to medical expertise, becomes even more necessary because without the patient's diseased body there is no factory, no medical system.

One way in which the rigidity of the system is maintained is through language itself. Different modes of discourse at the various levels of the system ensure that everyone remains in their assigned role. As knowledge increases, "when the individual scientist can take a paradigm for granted," and there is no longer a need to explain and justify every concept discussed, "the creative scientist can [...] concentrate exclusively upon the subtlest and most esoteric aspects of the natural phenomena that concern his group" (Kuhn 20). An increase in knowledge invariably also leads to the expansion of field specific language, and "communiqués will begin to change in ways whose evolution has been too little studied but whose modern end products are obvious to all and oppressive to many" (Kuhn 20). Findings will no longer be articulated in texts accessible to all;[14] "Instead they will usually appear as brief articles addressed only to professional colleagues, the men whose knowledge of a shared paradigm can be assumed and who prove to be the only ones able to read the papers addressed to them" (Kuhn 20). Making the language of medicine highly specialized means that the patient is also unable to equally participate in the medical conversation. Due to the immense volume of

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[13] Taussig also compares the patient to "automobiles on the assembly-line," the difference, he notes, is "that unlike automobiles, patients do think and feel, and that sickness is as much an interactive human relationship as a thing-in-itself" (100).

[14] By this Kuhn means that scientific findings will no longer be compiled and explained in relatively accessible textbooks such as Franklin's *Experiments...on Electricity* or Darwin's *Origin of Species* (20); "only in those fields that still retain the book, with or without the article, as a vehicle for research communication are the lines of professionalization still so loosely drawn that the layman may hope to follow progress by reading the practitioners' original reports" (20).

knowledge required to even minimally grasp a sense of modern illness, how most patients conceptualize their condition, and thus their own bodies, becomes critically hinged on the words chosen (and actions taken) by the 'experts.' And when the immune system is described as a military operation, complete with a 'chain of command-type' hierarchy based on gender, race, and class, the patient is more likely to accept the unequal power dynamic inherent in the way medicine is currently practiced.

Depictions of the body as battleground, and our immune system as the army defending against invasion by a foreign other, became fairly commonplace towards the close of the twentieth-century, and it may appear to the modern citizen as though it was always this way. Offering some historical perspective, however, Sontag notes that the military metaphor did not come into popular use until, naturally, the discovery of bacteria as causative agents of disease in the 1880's (66): "It was when the invader was seen not as the illness but as the microorganism that causes the illness that medicine really began to be effective, and the military metaphors took on new credibility and precision. [...] Disease is seen as an invasion of alien organisms, to which the body responds by its own military operations" (Sontag 97).

However, despite the germ theory of disease being well established by the 1870's by Louis Pasteur and Robert Koch, "there was no theory akin to our modern notion of immunological defense" until 1883 when Elie Metchnikoff formulated a new theory of "the relationship between host and contagious disease" (Tauber xiv, 1991). Himself an embryologist, Metchnikoff posited that mesodermal phagocytic cells, "wandering beneath epithelial surfaces and various interstices, recognized nonself elements and devoured them," and thus "the basis of Self emerged and immunological defense and surveillance were born" (Tauber xv, 1991). The word 'self' does not appear in the immunological literature however, until 1940 when Frank Macfarlane Burnet "tentatively" uses it in an article on infectious diseases (Tauber 242, 2000). It is not until 1949 that Burnet formally proposes the notion of immune self-nonself distinction in *The Production of Antibodies* (Tauber 242, 2000).

After the two world wars notions of illness became even more complex to mirror the changed social and political climate of the Cold War, made particularly possible by advances in immunology. As Emily Martin notes in *Flexible Bodies*, "The late 1940's and 1950's were times of heightened middle-class domesticity, as women were forced out of jobs they had held during the war and families often settled in newly burgeoning but isolated and commodity-oriented suburbs" (31). This sense of individual isolation is reflected in the shift from thinking about communal interactions and the health of the community, to thinking increasingly on the micro level, further and further into the deepest recesses of the individual body: "Whereas in earlier decades the condition of the whole city, for example, would have been of concern, by this time people were more apt to think in terms of the cleanliness of their own immediate environment, their own house and their bodies" (Martin 24).

Since at the same time advances were being made in immunology that showed the body to be a heavily defended fortress, one needs to ask whether these discoveries were made because the worldview at the time allowed science to ask the 'right' questions. In other words, to what extent did the SNS model come about because of objective science, and to what extent did images of families "hunkered down in low-slung houses surrounded by fences, [...] exhorted by the government to prepare for nuclear emergency" (Martin 31, 1994), contribute towards the development of this model? Considering the political climate during McCarthy's reign of suspicious terror that sought to *isolate* an enemy emerging from within the body politic, is it any wonder that the scientific gaze also turned inward, developing increasingly sophisticated technologies for peering within? Despite the altered worldview that has made conceptualization of context-based models of immunity possible, the persistent tenacity of the SNS paradigm can potentially be attributed to the current political climate of scrutiny, reanimated paranoia, and terror - especially in the wake of recent worldwide terrorist attacks.

Interestingly, as much as (North American) individualism was promoted in the Cold War era with this constant emphasis on the inner, there was also the constant peering outwards in search of the enemy: "Fear and anxieties about instantaneous 'collective annihilation' from external enemies armed with atom bombs and internal traitors who might aid and abet them permeated the age" (Martin 32, 1994). The notion of elaborate bodily defense was evolving simultaneously beside increasing knowledge of pathogenic complexity. Invading organisms - bacterial, viral, or other - became anthropomorphized into elusive and highly intelligent secret agents, always one step ahead of bodily defenses. And this view has remained the dominant one even into the twenty-first century. Most descriptions of HIV pathogenicity paint the virus as the most intelligent and evil of secret agents: as Sontag summarizes in her critique of the representation of HIV/AIDS "the AIDS virus ignores many of the blood cells in its path, evades the rapidly advancing defenders and homes in on the master coordinator of the immune system, a helper T cell" (Sontag 105). Again, what needs to be recognized is that this is not merely the objective scientific description of how the HIV virus functions, that there are other ways of describing this without invoking notions of good and evil, of instilling such fear. Unfortunately, one can argue that the underlying aim of such descriptions, conscious or not, is *precisely to inspire fear* in order to maintain the rigidity of the social, political and economic systems in place.

The web of interactions that link the political with the bodily are complex, but one can certainly envision in this instance how a perpetually frightened public might be advantageous towards certain economic goals. Supporting the claim that chronic fear is desirable in a capitalist society, Franklin notes how with increased mechanization of the work place, and replacement of the human with machine, the increase in production demands an increase in consumption. And although the creation of an insatiable consumer culture sops up some of this excessive product, the maintenance of "the infrastructures that support the preparations for war and violence" (Franklin 76) ensures the uninhibited flow of capital: "In all-out war, expenditure is all-out, unprudent - war being defined as an emergency in which no sacrifice is excessive" (Sontag 99). But to justify the ridiculous amount of funding allocated to war preparation (rather than into the education system, health care, housing, etc.) there must be a sense of threat:

> ... once a country has embarked on developing an arms production system, it falls upon the government to provide the wherewithal over a long period of time. [...] To keep such technological activities going, public funds have to be committed

> and expended. To keep the public funds flowing, justifications are needed. And this generates *the need for a credible long-term enemy.* (Franklin 78)

This enemy "must warrant the development of the most advanced technological devices. The enemy must be cunning, threatening, and just barely beatable by truly ingenious and heroic technologies" (Franklin 78).

The similarity between this description of a non-specific enemy, and that of the HIV virus quoted above, is striking. In both instances the language used "is the language of political paranoia, with its characteristic distrust of a pluralistic world" (Sontag 106). The 'us versus them' mentality on the macro level of nation state is perfectly reflected on the micro level of immunology with the SNS model: "The obvious connection between the timing of the advent of the self/non-self theory in the years following the Second World War and the assumption of the need for defense against difference calls attention to the ways in which social conditions may have influenced the inception and acceptance of this theory" (Weasel 31).

The social effects of promoting this view of a self-obsessed, hostile immune system - the one very much in operation even today - are wonderfully articulated by Peter Rodriguez, an epidemiology graduate student interviewed for Martin's *Flexible Bodies*:

> the military motif is an unhealthy way of constructing it because ... it supports the military kind of power structure and sexism of society....I think another effect of this military conception of the whole thing is it puts the conception into that of a foreign invasion, and there's this outsider that we don't like who's in our midst, and we want them to get out, and we have to resort to violence to get rid of them. I think that only sparks violence against people. I think that only supports everyone's homophobia. I think it only supports everyone's xenophobia. (Martin 69)

What makes the equation of the biomedical with the social possible, is that the cellular world is thought to represent a 'natural' state of being, and thus represents the natural way of interacting with other human beings. The same sort of reasoning also applies whenever animal behavior studies are used to justify or condemn a particular human behavior: "the nature of truth is seen to lie in the truth of nature, and not in some critical way as dependent upon the social organization of facts and nature" (Taussig 103). Rarely is it ever admitted that certain metaphors and language are ascribed to the immune system *as a way* of naturalizing human behavior, and especially of naturalizing power dynamics; as Weasel notes "the discourse of science serves to reinforce prevailing social and cultural stereotypes, making them appear 'natural'" (30).

With the discovery of antibodies in the 1890's the immune system began to be described as an active system, rather than one where "the pathogen is seen as acting by itself to produce immunity in an otherwise inert host" (Martin 33, 1994). This realization of active participation in disease, however, made it even easier during the Cold War era to describe the immune system as being as obsessed with distinguishing self from nonself as the politicians were. The first version of the SNS model of immune function, introduced in the late 1950's by Burnet, proposed that recognition of *foreign* antigen leads to B and T-cell activation (Matzinger 5, 2001). Suddenly, the body is posited as a kind of "police state," with immune cells ("The human body's police corps") "programmed to distinguish between bona fide residents and illegal aliens" through recognition of cell surface molecules - "likened to speaking a national language" (Martin 54, 1994). Worse still, the discovery of the immense antibody repertoire (something on the order of at least ten trillion different proteins recognized by immune cells), "prepared in advance against any possible eventuality, allows the immune system to be seen as an anticipatory system" (Martin 36, 1994). And naturally, the anticipatory nature of the immune system can now be used to further justify long-term military spending, 'just in case.' The way the 'police state' metaphor is set up, unfortunately, also lends itself quite well to the "conception of the nonself world as foreign and hostile" (Martin 53, 1994). Thus, the "The maintenance of the purity of self within the borders of the body" (Martin 53, 1994) can be seen mirrored in the housewifely cleaning frenzy that began in the 1950's (and continues today), and in the hostile national policy that led to the expulsion of many 'suspicious' characters from the United States (which again, continues today, especially post 9-11). Autoimmune disease is further problematized by this notion of purity within, for how does one expel oneself from oneself? The othering of the contaminating self (autoimmune cells) does little to clarify this conceptual dilemma, since complete removal is still problematic, and the 'other' still originated from self.

Using the logic of the SNS paradigm, however, it is precisely the said anticipatory nature of the immune system that makes AID possible. The crucial assumption made in the classical SNS model of immunity, is that "each individual's immune system 'learns' the difference between self and nonself early in life" (Matzinger 4, 2001). This means that self-reactive T and B cells are deleted early in their ontogeny, and then only cells unresponsive to self are allowed to remain and mature (Matzinger 4, 2001). But the mere existence of AID argues against this point. The plethora of various diseases where a robust immune response is initiated against some component of 'self' would argue that self antigens are very much a part of this vast antibody repertoire. The SNS view of immunity therefore makes it possible to argue that autoimmunity arises because the system is so paranoid and fearful of otherness that it must anticipate invasion from every conceivable source, including from within. Thus the fear of the foreign other becomes extended to the fear of oneself.

It is interesting to muse upon whether and how the sociopolitical situation prompted the 'discovery' of AID. In order to start looking for auto-reactive immune cells, the scientific mind (meant in a collective sense) had to accept this as a possibility. And seeing how the social context can set the precedent for the kind of original research done and consequent models proposed, the idea of 'the enemy within' probably arose out of the wider social context (if nothing else, the verbal formulation of AID as traitorous to self certainly did). Returning to the notion that perpetual fear may be economically advantageous in some situations, and that the construction of a credible enemy facilitates this process - the exact identity of the enemy is therefore bound to shift endlessly. Noting how "new enemies will quickly appear, to assure that the infrastructures can be maintained," Franklin discusses "the ease and speed of the transition" whereby "The Red under the bed has been replaced smoothly by the grass in the grass" - or how the Soviet nuclear threat was replaced suddenly by the 'war on drugs' (79).

The cycle of marriage and divorce that continually relinks the phrase 'war on' to a new partner, thereby justifying massive expenditure in the name of national security, has also been noted by Sontag: "the transformation of war-making into an occasion for mass ideological mobilization has made the notion of war useful as a metaphor for all sorts of ameliorative campaigns whose goals are cast as the defeat of an 'enemy'" (99). What the construction of the immune system as a perpetual war has made possible is the internalization of this emergency state. Although foreign enemies (bacteria, interesting new viruses like SARS, prions) still exist, they are also no longer necessary - all of the elements for the construction of chronic fear are present from birth through the ownership of a body, and unlike with foreign enemies, the threat from within is lifelong.

Recognizing that "the enemy does not have to be the government or citizenry of a foreign state. There is lots of scope - as well as historical precedent - for seeking the enemy within," Franklin predicts the "turning inward of the war machine" (78). Though not explicitly intending to use the term 'turning inward' to mean the conceptual militarization of the body, the phrasing nonetheless lends itself nicely to discussions of AID. If the aim is to inspire paranoia, then why stop at the border of the skin? If one is turning inward, then why not turn keep turning inward until one has delved deep into the body, into the 'core' of self - one's own cells? (Remember that in lupus an immune response is initiated against self DNA residing in the very nucleus of the cell). I do not mean to imply that AID is nothing more than a political fiction, but that there is immense opportunity, if the creation of enemies is the goal, to describe it in political terms: "In some cases, this occurs because normal cells have been physically invaded by a pathogen and altered in some way that causes the immune system to regard the cells as foreign" (Clark 108).

One of the effects of this kind of description is that since the cells are said to be participating in treason - but obviously incapable of answering for it - the inherent guilt becomes displaced onto the person in whom the cells reside: "the move from the demonization of the illness to the attribution of fault to the patient is an inevitable one, no matter if patients are thought of as victims" (Sontag 99). The anthropomorphizing of immune cells, of ascribing consciousness to them - traceable to the mid-17th century idea of the homunculus, or the little man inside the man[15] - allows for the cells to be portrayed as the moral representatives of the person - the actions of the child betraying the parenting. This kind of association is facilitated when "the immune system is viewed as 'recognizing,' 'remembering,' 'learning,' and 'acting,' - terms borrowed from the cognitive sciences" (Tauber 242, 2000).[16] Because cells are portrayed as these animated little beings, simultaneously autonomous from and intimately linked to the person, we somehow have the impression that "people are responsible for their health, even though they may feel guilty because they cannot control it" (Martin 124, 1994). And what this can foster is a kind of guilt-ridden compliance and powerlessness. Internalizing the notion that the immune system is committing a grave error, the patient might also feel

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[15] Clara Pinto-Correia offers an interesting retrospective on the homunculus in reproductive theory in her essay "Stange Tales of Small Men: Homunculi in Reproduction.": "In its crudest, initial form, the theory postulated that all organisms of all species, of all the generations to come, had been made by God during the six days of Creation, and had then been encased inside each other, in smaller and smaller sizes, much in the fashion of a Russian Doll" (225). In a similar way, we have retained and warped the idea that cells are small versions of the person.

[16] Tauber and Moira Howes appear to be locked in an interesting debate. In "Self, intentionality, and immunological explanation," and in "The Self of Philosophy and the Self of Immunology," Howes argues "that immunological language, including self-terminology, is neither genuinely anthropomorphic, nor perniciously teleological, and that "intentionality-as-aboutness, needs to be present if there is to be functional explanation in immunology" (Intentionality, 249). Tauber disagrees, stating that "We are 'selves,' but the immune system is a biological activity. And most saliently, the immune system is not a *human category*" (The Elusive Immune Self, 473). Admittedly, I find myself somewhere in the middle of this argument, since I do refer to 'communication' between cells, and propose that cellular interactions (especially as portrayed by the DM) can serve as examples for human interaction. In the end, I believe that the moment words are assigned to body parts, the body enters the realm of imagination, and we may always, as a way of organizing all the information and extrapolating meaning, imagine the body as a human category. My point is that if we are going to be doing this anyways, greater attention needs to be paid to both the semantics of immunology, and how we interact with one another.

that they are somehow at greater fault - "How can my immune system turn against me? You know? What have I done?" (qtd. in Martin 134, 1994). This sense of guilt becomes especially complicated since the patient (and the body) is still being simultaneously portrayed as the victim in all of this. Highly reminiscent of the ambiguous treatment of rape victims, as both innocent and somehow at fault, this forces the patient into an equally embarrassed, submissive position: "Victims suggest innocence. And innocence, by the inexorable logic that governs all relational terms, suggests guilt" (Sontag 99). Combine the idea of guilty victimhood with the fact that various medical personnel usually hold all of the knowledge of the disease and its treatment, that most doctors are still male and most patients female, then the relinquishing of control to expertise very much resembles a rape.

Granted, the comparison of medical intervention and discourse to rape is quite harsh, it does nonetheless suggest that current approaches to patient care may entail a kind of submission to violence. One of the features of prescriptive technologies is that they make reciprocity - "some manner of interactive give and take, a genuine communication among interacting parties" (Franklin 48) - very difficult. And just as reciprocity is ruled out when communication is mediated by technology such as television, the mediation of the body through technologies like the secluded microscope also makes reciprocity mostly impossible. In this absence of patient response whatever is done to the body in the name of medicine thus resembles other forms of bodily violence where consent is not given - a least a certain level of knowledge of the situation being a prerequisite for consent.[17] A major part of the problem is that in a field so expert-driven and fragmented as medicine, knowledge acquisition, if you are the patient, becomes very difficult. Thus "increasing public acceptance of the depiction of violence and cruelty" due to "technological exclusion of response" (Franklin 49) also translates to easier acceptance of actual *bodily,* emotional, and psychological violence in the medical setting.

Not surprisingly, the hierarchically ordered power dynamics inherent in a system based on the division of labor and expertise are also seen in immune system representations - perhaps as an unconscious way of naturalizing and justifying these social inequalities. Even though the various cells of the immune system have been repeatedly shown to be capable of performing one another's functions - a kind of system redundancy - the strict division of labor symbolic of prescriptive technologies is still usually imposed on them. And since division of labor on the social level is for the most part hierarchically ordered based on gender and class, thus so is the immune system. For example, the main players of immunity can be said to be the T-cells, B-cells, macrophages, and APC's (antigen presenting cells). The T-cells are described as the educated ones that "attend the technical colleges of the immune system" (qtd. in Martin 55), otherwise known as the thymus, bone marrow, and lymph nodes. T cells are the ones said to "stimulate B cells to multiply and produce antibodies" (Melander 226). They are not only more evolutionarily advanced, capable of higher functions such as memory, but also the ones that "penetrate" and "inject" (Martin 55, 1994). By contrast, the

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[17] In "Historical and Philosophical Reflections on Patient Autonomy" Tauber contemplates "what we in fact mean by 'adequately informed'" (312), concluding, sort of, that the term in elusive in the medical setting, and that "We, in fact, do not determine our own choices as much as choose among several that are presented to us. We delegate authority, recognizing that in this highly complex world experts must guide our choices and ultimate actions" (314) - meaning that the expert decides what is adequate information.

macrophage is most often portrayed as "a lower form of cell," the housekeeper that surrounds and digests foreign material in a seemingly indiscriminate manner (Martin 55, 1994).

Reminiscent of the division of labor in stereotypical male-female relations, as well as between the classes, this specialization in "housekeeping" also posits the feminine or lower class macrophage as less intelligent, less cultured, and less essential. The image of the macrophage "engulfing and surrounding" (Martin 55) (versus the penetrating T cell) additionally associates it with fairly passive femininity, invoking images of a prone female during the sexual act. The linking of masculinity "with the need to dominate and possess control over that which is 'other' in order to maintain the definition and identity of self" (Weasel 31) is especially apparent in immune system discourse. Further projecting 'masculine' traits onto the gender-neutral cells, the February 1990 cover of *Immunology Today* depicts the T cell monitoring the health of other cells (equipped with stethoscope and needle), kicking the obviously female B cell (sporting long eye-lashes and high heels), "frowning manfully" and kicking another T cell, and striding a macrophage, megaphone in hand calling for support (Martin 102, 1994, see figure 2). Thus even at the level of immune system cells, a high hierarchical ranking based on superior education and expertise seem to enable one to treat others (especially feminine others) in violent ways. And here too expertise gets the loudest, the only, voice; nowhere in this representation is there the impression that immunity is the result of a complex, egalitarian exchange of communication.

Returning to the discussion of medicine as a prescriptive technology, the rigidity of its prescribed roles, and the effect on the patient-expert interaction, I want to spend some time now on an article titled "The Language of Cells" by a pathologist named Spencer Nadler. A personal narrative of sorts - in which a surgical pathologist normally completely removed from patient care, but instrumental to the initial diagnosis, crosses the great divide of the 'microscopic tunnel' to make the rounds with a pediatric oncologist (Dr. Jerry Finklestein) who deals directly with patients on a daily basis - it quite eloquently demonstrates how the patient-expert interaction reflects the unequal nature of current descriptions of *immune* interactions, and more specifically, how cellular 'language' enables the medical expert, and only the medical expert, to converse with the patient's body.

Beginning with the admission, "As a surgical pathologist, I have spent my professional life evaluating tissue biopsies, rendering microscopic diagnoses of disease," Nadler vividly recounts the importance, but also the isolation, of his role:

> Conveying my biopsy diagnosis to the clinician - the family doctor or surgeon or internist - completes my task. The diagnosis is the end of the line for me; it marks the beginning of treatment for the patient. This sequence isolates me from illness. Clinicians tell me their patients' stories and the diagnoses I impose on them can fill me with vicarious sadness. I often feel the urge to climb the upright tunnel of my microscope, to connect with the personal side of illness. (513)

Interestingly, looking at the wall of photographs representing the children Dr. Jerry Finkelstein has treated - the human face of illness - Nadler climbs 'the upright tunnel' back to the cells: "As I look at the beautiful children he selects, I can't help superimposing images and growth patterns of tumor cells, visually linking children with their harbored tumors" (514). Repelled by the "lopsided nuclear faces that have sprung from hidden stem cells" (524) Nadler mentally isolates and separates the cells from the child. Initially seemingly innocuous, the word choice and imagery depicted in this short segment reveal the ways in which the *how* critically affects the *what*, and vice versa: the isolated pathologist using precision equipment to critically appraise cells isolated from a child's body - a child whose beautiful surface exterior at this point seems to betray nothing of the disease within. This kind of distancing "between the observer and the human object being studied" (Rosser 132) is also significant because it betrays the androcentricity of medicine: "Distance between the observer and experimental subject may be more comfortable for men who are reared to feel more comfortable with autonomy and distance than for women who tend to value relationship and inter-dependency" (Rosser 132). Though limited and somewhat simplistic, this view does question how gender affects the *way* medicine is done (whether the differences are innate or socialized being besides the point here), and thus the patient's role in the process.

A very important outcome of this distancing at all levels of medicine (including original research), is the disempowerment of the patient - and on some levels of the expert as well. Because diagnoses are made by specialists like Nadler, sequestered in their medical laboratory with only the patient's cells or fluids to 'converse' with, the patient has even less opportunity to participate in the medical conversation supposedly occurring for their benefit, on their behalf. The expert, although more able to deviate from the prescribed role than the patient (as witnessed by Nadler's narrative), is also somewhat restricted by the system,[18] hence Nadler's desire to connect with the human side of disease. The fact that he chooses to document this brief deviation from his role, and titles it 'The Language of Cells,' also demonstrates the need for communication.

Although Nadler's text deals specifically with cancer, the mindset and methodology revealed in this piece are indicative of medicine's approach towards the body more generally. Walking through the hallways Nadler notices the painted tapestry lining the walls, "rows of Mexican palm trees painted in brown and green" (523). In the desire to help families "baffled by abominable diagnoses" understand the complexity of a disease like cancer, Finklestein chooses his words carefully - though as Nadler says, they are "sometimes clichéd, even childlike" (518). Using the organic, though still objectifying, metaphor of the tree Finklestein states that "Remission is like cutting down a tree [...]. You see nothing of the tree above ground but as long as the roots remain the tree will grow back. [...] Leukemic cells will disappear from his marrow. We will continue chemotherapy for three years to get rid of the root system, the remaining leukemic cells we can't see" (524). The notion that the seemingly healthy body is a potential resevoir of discrete and autonomous units acting against the well-being of the whole is certainly the dominant view of diseases like cancer and autoimmunity where there is no foreign invader. Accurate identification and observation of these disease-causing cells then takes on extreme importance, and is made exceptionally difficult because aberrant behaviour must be gauged based on detailed molecular analysis. Thus,

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[18] For a discussion of how the changing, and often conflicting, demands of the expert role have affected doctor narratives see: Wear, Delese and Brian Castellani. "Conflicting Plots and Narrative Dysfunction in Health Care." Persp. Biol. Med. Summer 1999; 42(4): 544-558.

"Modern - that is, effective - medicine is characterized by far more complex notions of what is to be observed inside the body" (Sontag 123) than in the days of Leeuwenhoek's simple compound microscope.

One of the effects of diagnoses based on sophisticated gazing technologies is that the subject's experience of the body (both physical and especially mental) becomes trivialized - feeling healthy means next to nothing, since 'rogue' cells may still be present in the body, hiding. Thus, in Nadler's account the mother of the child in remission "doesn't smile until she's seen Rebecca's normal count for herself" (515). The body is thus being represented and read (again, primarily on the microscopic level) through the physical manifestations of disease rather than understood through the patient's verbal testimony - and hence the notion of cells speaking to the doctor in a language mostly incomprehensible to the patient.

What the tree analogy also implies is that illness, once diagnosed, may remain a permanent facet of identity - despite supposed medical attempts to remove the illness from the patient. The notion of an invisible diseased root-system means that not even the most sophisticated gazing technology will be able to see the disease that still surely lurks within. This is particularly true in the case of an autoimmune disease like MS or Lupus, where the initial diagnosis means patienthood (or the assumption of a static patient role) for life, even if the bodily and mental experience of the disease changes, or in the complete absence of symptoms (which is usually the case, since most autoimmune diseases are typically characterized by extended periods of 'remission' - again, rather than 'health' per se). And since the patient cannot trust bodily experience, the power to shape mental conceptions of patienthood hinges on the words of the experts. In this way the system guarantees that the patient role, on which everything depends, will be permanently occupied.

The desire to isolate and extricate the causative agent from the otherwise healthy body, to chop everything up into discrete autonomous units to be sorted accordingly into either of two piles - normal and abnormal - is interestingly reversed at one point by Nadler: "What can be done for David? Can he be extricated from his leukemia cells?" (521). Again, the emphasis here, much like in the original research described in the first chapter, is on the separation of parts from a more complex system. Nadler's interesting reversal of the customary phrasing (normally it would be said that the aberrant cells must be removed from the body, rather than personhood from the cells), betrays the idea, inspired by the SNS paradigm, that disease is always otherness (even when it is so clearly *not,* as in cancer and autoimmunity) and can - indeed must be - separated from the person at all costs. Interestingly, one can claim that just as research methodology subverts the notion of a static self, medical intervention also points towards the malleability of the body and the importance of context, even within the supposedly rigid boundaries of self.

However, medical manipulation, even while pointing towards the subversion of static models of the body, still raises questions about patient autonomy. Briefly, the "concept of autonomy - the idea that moral law can only arise from our own reason - begins and ends with Kant" (Tauber 306, 2001). The notion that "moral conduct is ultimately self-generated," and that "humans control themselves through their own moral reason, which is independent of subjective wants and needs" (Tauber 305, 2001), has in many ways become a thing of the past:

> Multiculturalism, pluralism, tolerance for widely diverging moral systems is the ethos of our own culture, and the Enlightenment dreams of reason seem just that, dreams. Furthermore, confidence no longer exists in a moral imperative from which all humans might expect to find some common understanding. The Kantian idea of autonomy and its operation arose within the culturally homogeneous social and intellectual milieu of the European Enlightenment. That milieu is gone forever, and the concept, accordingly, has metamorphosed over the past two centuries. (Tauber 307, 2001)

What the term has metamorphosed into, Tauber contends, is "individuals acting in self-assembly and self-governance under the principle of permission" (308, 2001). Meaning that "the moral focus has shifted from the individual making independent choices to the individual consenting to be part of collective decision-making" (Tauber 308, 2001) - "our individuality has been subordinated to collective bargaining." I find the idea of 'permission' particularly interesting (because I agree that that is largely how autonomy functions in a society as infrastructured, fragmented, and dependent as ours) and at the same time puzzling: what exactly are we giving permission for? To whom? What does being a 'part of collective decision-making' entail? What happens if we refuse to give this permission?

In the medical setting autonomy is particularly problematic because the patient is most often not in a state to participate in this 'collective bargaining.' Language is the most obvious barrier to full participation: "Medically unsophisticated, or at least untrained, patients cannot be expected to fully understand and integrate the vast technical and scientific information required to make informed clinical decisions" (Tauber 311, 2001). Whether or not this is inevitable is of course debatable. Another reason patient agency is problematic pertains to emotional vulnerability: "Frightened and in psychological if not also physical distress, the patient is fundamentally *dis-eased.* To think clearly - rationally and dispassionately about personal life and death choices - is all too often beyond normal expectations" (Tauber 311, 2001). Although I do believe this emotional distress can be a catalyst for a reconceptualized autonomy, I also agree with Tauber in that this dis-ease often renders a person too catatonic to subvert the prescribed patient role. In many ways then medicine is about "tranquilizing the disturbance that sickness unleashes against normal thought" (Taussig 109). What is therefore being cured through the prescribed doctor-patient relationship is more "the threat posed to convention and society" (Taussig 109) than disease per se - "it is the clinical construction of reality that is at issue" (Taussig 107).

The idea that David can be extricated from his own cells paints the patient to be as passive and manipulable as cells in a petri dish. Although comic, the image of a person lying on a petri dish or microscope slide, being plucked out of the surrounding muck with a pair of tweezers, the undesired cells left behind, lends further support to this characterization. The description of David's leukemic cells on drugs as "faltering inside him, gravely hampered by dire transformations, complexities that rival the cosmic explosions of stars" (526), eerily mirrors the final description of David himself: "subjected to a toxic chemical onslaught. His green eyes are glazed by the fierce destruction, his body a helpless receptacle" (528). This sense of helplessness is further shared by David's mother, who "is losing control of her child's care. This responsibility is being usurped by strangers" (523). In the "unfolding silence" that is an acceptance of authority, of the prescribed passive patient role, it becomes clear that the patient does not have a voice in this medical conversation.

The inequality of the doctor-patient relationship is further emphasized when Nadler describes himself as "exhilarated by working with a broader canvas - the patient" (527). One of the most obvious implications of this statement is that once the patient has submitted their body to medical expertise, she must 'permit' infinite manipulation, and must *herself* become infinitely malleable. Another implication is that the patient is somehow blank, that the expert decides what image the patient will be made to resemble, rather than assuming that the patient is *already* a full canvas (and being careful how their brush might alter this 'painting'). Thus, although the notion of doctor as artisan appears to seize a holistic role for the medical practitioner, it is unfortunately at the expense of the patient who becomes objectified and evacuated of agency. Taussig sums it up well when he remarks that the expert-patient relationship "is a strange 'alliance' in which one party avails itself of the other's private understandings in order to manipulate them all the more successfully. What possibility is there in this sort of alliance for the patient to explore the *doctor's* private model of both disease *and* illness, and negotiate that?" (107). Ultimately, however, Nadler decides he is "out of place in the grandness of it" (527) and decides to retreat once more behind the microscope, to his own role, re-establishing the prescriptive nature of this technology and its all-encompassing isolation.

Though David's mother's response in the face of medical authority shows how "the division of labour characteristic of prescriptive technologies has resulted in the acculturation of people into a culture of conformity and compliance" (Franklin 94), imagining a holistic approach to something as increasingly complex as medicine also seems problematic, if not impossible. Part of the problem, again, is that the prescriptiveness of the biomedical field is mirrored in cultural institutions, and vice versa. Thus, it becomes increasingly difficult to even envision alternate ways of caring for the ill, and *being* ill, when adherence to prescribed roles is continually naturalized through reiteration. And here is where the potential of alternate explanations of immunity such as the Danger Model to affect not only the personal experience of illness but also wider social relations, becomes increasingly apparent.

Despite the repeated emphasis on division and fragmentation, what I have also been attempting to demonstrate thus far has also been the incredible interrelatedness of the systems that construct our reality; the political bleeds into the 'objectively' scientific, the economic injects itself into models of immunity, depictions of the immune system infect social interactions, and technology mutates everything. Therefore, imagining an immune system not based on hierarchy, violence, and oppression will also entail imagining "work that is less prescriptive, workplaces that are less hierarchical, relations that are less rigidly ranked" (Franklin 104). In other words, alternative models of immunity based on equality and egalitarian communication will most likely emerge alongside social practices that promote the same thing.[19]

One of the things that makes Matzinger's DM such an attractive alternative to the military models of immunity, is precisely that the model seems to come hand in hand with more egalitarian social interactions. The way Matzinger has gone about promoting and developing the model very much mirrors the message of the model itself: "Immunity is a conversation not a war." Thus, rather than fearfully defending the model against attack Matzinger makes herself and the model - and thus also the exclusive, expert-driven field of immunology itself - 'a welcoming habitat':

> I hope that readers with criticisms, comments, data that fit or don't fit with the model, suggestions for experiments, critiques of previous experiments, etc. will find it interesting, worthwhile and fun to converse there with me and other readers. In the past, it has often been the accumulated knowledge of minute details that led to the understanding of a complex system, but no one of us can possibly know all the details of the immune system's wondrously complex machinations. Perhaps, by pooling our collective wisdom and our collective knowledge of the details, we will uncover connections that would otherwise remain hidden. (3, 2001)

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[19] In her exegesis, "Dismantling the Self/Other Dichotomy in Science: Towards a Feminist Model of the Immune System," Lisa Weasel contrasts the self-nonself model of immunity and Matzinger's Danger model within the context of three strands of feminist epistemology: feminist empiricist claims, feminist standpoint theories, and feminist postmodern positions. One of her main conclusions is that "while scientific practice and scientific content are in many ways interlinked, oftentimes the contextual reading of scientific content can alter or expand upon its meaning without altering its practical origins" (41) - meaning that we do not need to live in a feminist world to have a feminist science, or in my case, that we do not need to live in a culture based on equality and egalitarian communication to construct an image of an immune system based on those things. Although I do agree that to a very limited extent current scientific findings can simply be re-articulated to reflect an alternate sociopolitical agenda (whatever that happens to be), at some point this logic breaks down because the kinds of questions scientists ask, and the kinds of experiments performed, will still be based on the original paradigm. How often do feminists claim that we can keep forever re-articulating patriarchal systems of knowledge without examining or attempting to subvert their origins?

Interestingly, the 'our' and 'we' throughout Matzinger's writing does not merely refer to the experts of the field, but literally everyone; the connections sought seem to be as much about actual human conversation and collaboration as about immunological epiphanies. Since notions of how the immune system functions eventually impact most members of a given society, does it not make more sense to develop these models collectively? Thus, as Matzinger "wandered the world talking about the model, listening to other people's comments, and thus learning new details of the immune system," she not only conversed with the experts - the "immunologists, virologists, parasitologists, physicians" - but also with the students and taxi drivers that she encountered (2, 2001).

Reflecting on motherhood, Franklin notes how women's work, especially within the home, "depends strongly on personal judgment, on knowledge of the total work process, and on the ability to discern what the essential variables are at any one time" (104). Based on the observation that women in particular have more "historical experience of situational and holistic work" (Franklin 104), it is very tempting for me to state that a model of immunity based on situational assessment and communication being developed by a female immunologist seems fitting. Although I do believe that Matzinger's gender, and especially her immigrant status, contributed towards the formulation of the Danger Model, I do not want to assume an essentialist stance by claiming that *only* a woman could have done this. As noted, Niels Jerne was similarly dissatisfied with the SNS immune distinction and attempted to re-write the immune story twenty years prior to Matzinger. I believe the ability to discern the essential variables in a given situation and to make decisions based on context is a more universal *human* requirement. Thus, the non-military based metaphors of immunity offered in Martin's text that promote "a body that actively relates to the world, that actively selects from a cornucopia of continually produced new antibodies that keep the body healthy and enable it to meet every new challenge" (Martin 37), reflect the importance of context generally in judgment.

What is immediately apparent from this description, is that here the emphasis is on the body being an active participant in immunity, rather than a passive recipient of violence (from both the 'masculine' immune cells and infectious agents). According to Franklin, schemes that require "knowledge, experience, discernment, and an overview of a given situation. [...] are, more often than not, intended to minimize disaster rather than to maximize gain" (83). Although both Franklin and Martin's texts were written prior to Matzinger's articulation of the danger model, its anticipation is unmistakable: "The Danger model does not allow an army to control immunity. It expands the definition of the innate immune system to include the extended, highly interactive family of bodily tissues. It allows for a flexible system that adapts to a changing self while launching immune responses to dangerous pathogens" (Matzinger 8, 2001). And at the heart of the danger model lies the notion that immunity is a complex process where every cell, every molecule produced, is important - "We brought into the conversation every tissue in the body" (7, 2001). Increasingly "attention is being paid to highly complex systems - from the rain forest to the animal body - that function in a self-organizing, dialectical interchange within itself (however its boundaries are drawn) *and* with its 'outside' world" (Tauber 244, 2000). This 'context-based' model of immunity "means, simply, that all action is determined by context, where agent and object play upon each other" (Tauber 244, 2000), and where communication is key.

What the notion of conversation allows is the possibility of defragmentation, and at least to some extent, a reorganization of power relations. Again, I am not claiming that there is a perfect, whole version of ourselves floating around somewhere; the thinking mind largely operates through fragmentation. Rather, it is a matter of degree and kind and the subsequent effects on quality of life. As will become especially apparent in the third chapter, the fragmentation of the *mental* body that often results with the current expert verbalization of autoimmune disease can severely impact a patient's life for the worse. If every cell within the body is brought into the conversation, is capable of interacting on some level with virtually every other cell, then fragmentation of these same cells and their molecules into autonomous entities is ridiculous. Or, more accurately, ascribing guilt for a process as complex as autoimmunity onto a single cell type seems ridiculous. If a T cell has receptors for molecules produced by B cells, if a macrophage has receptors for adhesion molecules that bind it to the epithelium, if muscles can communicate with brain cells, then what we are looking at is effectively one endlessly open system: "each cell type is led by the responses of the other cell types to respond with more or less vigor, and with different response molecules and behaviors. The immune system, in short, responds to its own responses as it orchestrates inflammation. This is corespondence. Corespondence is decision-making by committee" (Cohen 218).

Although Cohen still anthropomorphizes immune cells, this portrayal of immunity emphasizes perpetual communication, rather than a patriarchal system where only certain cells dictate the response. Again, this may merely be an issue of semantics, but the point of view that it lands us in is completely different - "The emphasis shifts from the various roles played by the parts of the immune system to 'the most remarkable feature of the immune system ... the system itself - the functioning of diverse elements as an efficient, effective whole. [...] a complex system held together by communication and feedback, not divided by category and hierarchy" (Martin 61, 1994). In this way *there is no other.*

From an immunological perspective the rather radical claim that there is no other is supported by the fact, as early immunologist Ludwik Fleck (1935) notes, that "A completely foreign organism could find no receptors capable of reaction and thus could not generate a biological process" (qtd. in Martin 109, 1994). Similarly, the fact that virtually all of the body's cells contain within its DNA the means of recognizing and interacting with other cells means that there is no foreignness, no 'otherness' among them. The immense antibody repertoire that was used to naturalize the sociopolitical preoccupation with foreignness, can therefore also be understood as the immune system seeing only self, of anticipating "inside 'self,' every variety of the 'nonself' that it could ever meet"; " This approach moves from a paradigm of the immune system not seeing the self (lest it attack) to a paradigm of the immune system not seeing the foreign" (Martin 110, 1994). Because we contain within our DNA the code for the receptor that enables immune cells to recognize and interact with, for example, *Mycobacterium tuberculosis*, therefore *M.tuberculosis* is self. And the autoreactive T cell is not something foreign that was once self tolerating other self and is now 'attacking' self as though it were foreign - this kind of description belongs to the realm of imagination, fed on James Bond and Cold

War propaganda. Accepting autoimmune cells as part of self may not make the physical experience of the disease any different, but it may mean that while symptoms are occurring, impacting the quality of life, the patient is less likely to think of the diseased body, life, and self as invalid.

Another way of understanding this incredible interrelatedness is through quantum theory. David Bohm (a protégé of Einstein's), and Karl Pribram (a neurophysiologist at Stanford University), proposed a theory whereby everything in the universe is linked to everything else in ways even Einstein did not anticipate. Observing the behavior of plasmas (a gas dense with electrons and positive ions) Bohm noticed that "once they were in a plasma, electrons stopped behaving like individuals and started behaving as if they were part of a larger and interconnected whole" (Talbot 38). Rejecting the classical scientific view of "the state of a system as a whole as merely the result of the interconnection of its parts," Bohm instead proposed that "the behavior of the parts [is] actually organized by the whole," that the whole is "in some ways the more primary reality" (Talbot 41). Similarly, a macrophage will behave very differently when bathing only among other macrophages in a minimal pink liquid (*in vitro*), versus when in the body during a bacterial infection. In fact, the behavior of any body cell at any moment in time will be dependent on the state of the system as a whole, and since the state of the system is in continual flux then a cell will never behave exactly the same way twice throughout its lifetime; and one of the main determining factors of behavior is, of course, interaction and communication with other cells: "the immune system continuously exchanges molecular signals with its interlocutor, the body. Additionally, both the body and immune system adjust their behavior in the light of the signals each receives and sends to the other" (Cohen 217). Knowing this, which every immunologist intuitively must, it makes our system of experimentation (as described in the first chapter) and knowledge acquisition seem even more archaic. And it also subverts the notion of static prescribed roles: from moment to moment behavior of humans and immune cells depends on context.

The image of body as a fortress, able to seal itself off from otherness, is therefore also a poor representation of how we are increasingly conceptualizing the body: as Bruce Kleiner, an M.D. and researcher, accurately observes - "all the time the integrity between the inside and the outside is violated, like when you have a bowel movement, bacteria get into your blood" (Martin 107, 1994). The term 'violated' here is also inappropriate, since it still implies that contact with microbic entities is always bad. Instead, we can think of it more as "a healthy meeting of the outside and the inside as opposed to keeping it out because, of course, it's going to be coming in," as acupuncturist Anthony Humphreys proposes (Martin 88, 1994). As in quantum theory, we can also state that if we are this endlessly open system, in intimate, constant contact with our environment, if microbes can simply pass through and interact with body cells and affect their behavior, then these microbes (for whatever length of time) are also part of self, part of the same system - like particles in a plasma.

Another crucial difference between the context-based models of immunity and the SNS paradigm, is that the former can accommodate change:

> At one level, organisms live with rich symbiotic relationships, but even more fundamental to their so-called identity, they must constantly adapt to environmental stresses and challenges. Within the constraints of programmed genetic structural and functional capacities, the organism responds along a continuum of behaviors and thereby changes. In the case of the immune system, we refer to 'learning' and 'memory' to capture how the system must be adaptable and in its adaptation, change. (Tauber 244, 2000)

Illness, in a sense, is change itself - the body responding and adapting to context. And if constant change were accepted as a 'normal' aspect of biological existence, then physical change due to a disease like MS might not necessarily lead to a complete rejection of the diseased self, but rather to an embrace of the continually changing self.

Thinking of the body as an open system, rather than a fortress, also has some obvious subversive political implications. If "There is no need to make a response to a virus that enters a cell, makes a few copies of itself and leaves without doing any damage," and we might, in fact, "even want to welcome such viruses for the genes that they could bring us" (Matzinger 4, 2001), then what happens to concepts of the enemy? And if we can find it within us to imagine microbes as self, then can we not welcome autoreactive immune cells, the supposedly ultimate enemy within, back into self? And if we move away from the notion of AID as 'an attack on self,' then how else might we explain autoimmunity without reversion to military or self-nonself terminology (especially considering that tissue damage is actually being done and the patient does feel ill)?

Although the DM is able to explain other immune phenomena (such as transplantation and pregnancy) much more fully than AID, it does still offer some alternate explanations. One possibility is that "some autoimmune diseases may be caused by mutations in genes governing the normal physiological death and clearance processes" (Matzinger 304, 2002). Since cells that die a 'bad death' due to some kind of stress, rather than normal senesence, emit stress signals, and if non-stressed cells begin to emit these signals due to mutations in the DNA, then the response of immune cells would still be to clear these cells, resulting in autoimmunity (Matzinger 304). This might be a preferable way of viewing AID because it implies not only that tissues themselves have a lot of say in immune responses (potentially most of the say according to Matzinger), but also that "In these cases, the immune system is not at fault; it is doing its job of responding to alarm signals (but in these cases, to the detriment of the host)" (Matzinger 304).

In fact, once we reject the idea that immunity is based on SNS discrimination, then the existence of autoreactive immune cells not only becomes normal, but potentially beneficial in a specific context. For example, we know that autoreactive dendritic epidermal T cells "seem to be there to produce cytokines that heal damaged skin" (Matzinger 304); "T cells specific for brain proteins can lessen the secondary damage that follows neural injury" (Matzinger 304); "Healthy individuals are populated naturally with autoantibodies and autoimmune T cells" (Cohen 216); "Tumor antigens, for the most part, are normal self antigens, and tumor immunity is mostly autoimmunity" (Cohen 216); and despite years of research we still have not been able to identify the supposedly foreign targets of circulating gamma delta T cells, leading to the possibility that such tissue-localized cells are part of normal immunity (Matzinger 304).

Thus, "if we move from the idea that every lymphocyte should be directed against non-self antigens whose appearance stimulates the response, and consider instead the possibility that immunity is controlled by an internal conversation between tissues and the cells of the immune system, we may regain a renewed sense of the self that we have lost" (Matzinger 304) - literally! This kind of analogy lets us view autoimmunity as the result of a conversation that took place between tissues and immune cells, where immune cells are responding not on their own, as double agents with a personal agenda counter to the well being of the whole, but rather in concert with all of the other cells in the body. And rather than acting in a destructive manner, this kind of immune response is also (like the innate and adaptive immune response) acting in a manner that has proven evolutionarily beneficial in some way - autoimmunity is too prevalent for it to simply be a 'mistake.' By first accepting that this is an immunological reality, that autoreactive cells are a part of self (and calling them something else), it may allow us not only to ask different kinds of questions in original research, but also to articulate AID in much less disparaging terms to the patient, one less conducive to the fragmentation of the body through the scapegoating of individual cells, and individual people.

Chapter Three: Domestic Subversions

> My defence will simply be that he was, and always has been, a devil embedded in my flesh, that he was an incarnation of what the scriptures enjoin every man to expunge from his being. My defence will be that it was my right - as it is the right and obligation of every man - to expunge my own evil.
>
> Barbara Gowdy, "The Two-Headed Man"

Having discussed in the first chapter how basic biomedical research methodology is influenced by, and simultaneously has the power to influence, social ideology and personal conceptions of the body, and having discussed in more detail in the second chapter the nature of this relationship, I now want to examine the personal side of autoimmune disease. Specifically, I want to use first person personal narratives written by people living with AID to address whether and how the tendency to fragment the body in contemporary medicine affects how the body and disease are imagined. Central to this chapter is an examination of the experience of illness in light of the different immunological paradigms - the SNS paradigm and the emerging context-based paradigm of immunity: how has the SNS paradigm (being the dominant view of immunity for the past 50 years) influenced the experience of autoimmune disease? Does the SNS view of immunity 'fit' with the actual experience of illness in this cultural moment? How might the context-based models of immunity such as Matzinger's DM influence the experience of autoimmunity - and also the strategies of representation people employ to negotiate illness?

The role of language in the construction of these personal body stories must therefore necessarily comprise a significant portion of the chapter not only in terms of the words used, but also *how* language is used in the medical setting. As I attempted to show in the preceding chapter, the way we communicate with one another has tremendous implications for how we view the world and our body. Thus, communication - between the experts, between experts and the patients, between patients, and of course between patients and their family/caregivers - will also continue to be an important aspect of the discussion. And finally, the significance of the illness narrative genre itself must be examined - why write about the experience of illness? How does writing about it change the experience of it, particularly in the case of autoimmunity?

Because this chapter also deals with notions of selfhood and its fragmentation, I want to reiterate that I am not proposing that there *is* some ultimate, perfect wholeness that the ill have lost and the healthy possess. But unfortunately the way disease, especially autoimmune disease, is usually articulated encourages the patient to think in these terms. Selfhood, for the purposes of this discussion, is therefore a certain mental conception of oneself through which all experience is filtered (and we like to imagine this self as integrated). This imaginary self (which one could say is the only self that matters) can and does change over time, much as the physical self does. However, current notions of a constant immunological self from birth limit the extent to which change is allowed. The Danger Model may better represent the experience of illness because its main tenets were formulated based on the changing body. What I am most interested in, therefore, is how the *imagined* self is constructed and affected by immunological discourse.

The importance of the expert-patient interaction in guiding the patient's construction of this imagined (diseased) self cannot be over-emphasized. As discussed in the second chapter, the nature of our interactions with others critically influences how we view ourselves. The relationship with the medical expert is particularly seminal to imagined selfhood because doctors are invested with the power to explain our bodies to us (and, for the most part, doctors still use the language of self-nonself to do this). In the automobile factory analogy of medicine the doctor is the one that explains to the patient the precise nature of their specific role. As touched upon in the second chapter, the vulnerability of illness can make the patient much less likely to attempt any subversion of this prescribed role. Because frightened "Patients want to facilitate the process of healing, and to do so they usually readily admit their dependent status" (Tauber 314, 2001), resistance (or even conscious notice) of how medical discourse affects the imagined self is much less likely. The first-person illness narrative is therefore usually a retrospective attempt at inclusion in the medical conversation in which the patient was originally silent. Proficient, plentiful use of medical terminology is thus a common element in these narratives.[20]

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[20] Beginning with the admission that the body-self is *choice* that is acted out, Arthur W. Frank in *The Wounded Storyteller* goes on to list four types of body "puppets" (40): the disciplined body "defines itself primarily in actions of *self-regimentation,*" attempting to "compensate for contingencies it cannot accept" (41); the mirroring body, in turn, "defines itself in acts of *consumption*" in an effort "to recreate the body in the images of other bodies: more stylish and healthier bodies" (43); the dominating body, having assumed the contingency of disease, but not accepted them, "displaces rage against contingency onto other people" (47); and finally, the communicating body, having accepted contingency and illness as a part of life, not only "sees reflections of its own suffering in the bodies of others," but also feels obligated towards others "who bear the mark of pain," needing to communicate with and *through* their bodies - thus the communicating body "is fully *associated* with itself": "a problem within the tissues pervades the whole life" (49). Based on these four types of bodies in illness, Frank then proposes three types of narratives: the restitution narrative in which health is accepted as the "normal condition that people ought to have restored," marked by "talk of tests and their interpretation, treatments and their possible outcomes, the competence of physicians" (77); next, the chaos narrative is essentially "the opposite of restitution: its plot imagines life never getting better" (97); and finally, the quest narrative is about meeting suffering 'head on,' and conceptualizing illness (and the storytelling) as a journey/quest in the "belief that something is to be gained through the experience" (115).

However, because "the patient is fundamentally *dis-eased*" (Tauber 311, 2001) - especially in the case of AID where the patient is told they are literally rejecting themselves on a physical level - the opportunity also exists to question not just this new dis-eased self, but also the healthy self the patient is urged to recuperate. As "dependent and anxious" as the sick person may be - "malleable in the hands of the doctor and the health system, and open to their manipulation and moralism" (Taussig 86) - the fact that disease throws an individual into a "vortex of the most fundamental questions concerning life and death" (Taussig 87) may also lead to a personal reformulation of identity. Because illness often nullifies the imagined coherence of the healthy self - especially in instances of autoimmune disease where the self is literally said to be fractioned by civil war - the need to regain a sense of integrated identity may further drive the patient to assume the patient role, which may seem preferable to the 'vortex' of uncertainty (sometimes a concrete diagnosis, even if it is a bleak one, can give the patient a sense of peace).

Conversely, as much as this destabilization of identity "gives the doctor a powerful point of entry into the patient's psyche, and also amounts to a destructuration of the patient's conventional understandings and social personality" (Taussig 87), it also allows for a personal reformulation of identity *precisely* for the same reason: as Arthur Frank observes in *The Wounded Storyteller* - "Just as illness almost invariably plunges the body into lacking desire, illness can instigate new reflections on how to be a body producing desire" (39). If the patient's social personality based on (healthy) conventional understandings of the world is rendered null and void, there is always the possibility that rather than accepting the prescribed patient role as compensation the patient opts instead to formulate a completely different and unique identity based on their own personal experience of the world - one which *includes* the experience of their dis-eased body. Not only that, but a disease like MS which may disable the patient in progressive increments also allows for a continuously shifting identity based on these bodily changes.

Although technology today remains rigidly prescriptive (perhaps even more so), somehow we have begun to conceive of our lives and bodies as fluid, context-dependent. In this way the Danger Model may better represent the experience of illness generally because it allows for the body to change throughout a lifetime, rather than remaining rigidly fixed in a specific role: "Within the constraints of programmed genetic structural and functional capacities, the organism responds along a continuum of behaviors and thereby changes. In the case of the immune system, we refer to 'learning' and 'memory' to capture how the system must be adaptable and in its adaptation, change" (Tauber 244, 2000).

In this instance the illness narrative serves more as a testament to the patient's resistance than a claim to medical legitimacy. At the heart of this resistance, as witnessed by Nancy Mairs' narrative, seems to be an attempt to validate the experience of (autoimmune) disease as a legitimate aspect of the life being lived. In order to do this in autoimmunity, the patient must reject the notion that they are rejecting themselves on a cellular level, and that separation from this autoreactive part of themselves will restore them to 'natural' selfhood. Instead, the disease is viewed simply as something that *is*, for whatever length of time, thus not excluding the possibility of medical treatment altering the course of the disease, but also allowing the patient to adapt to, and accept, their continually changing body.

I want to begin in a somewhat chronological manner with Henrietta Aladjem's narrative *The Sun Is My Enemy: One Woman's Victory Over a Mysterious and Dreaded Disease* (1972). Diagnosed (sort of) with Systemic Lupus Erythrematosus (SLE) during the Cold War era of the 1950's, Aladjem's tale makes it possible to look at the experience of illness during a very specific social and political climate. It will then also be possible to compare Aladjem's narrative with those written more recently.

Recollecting from the previous chapters how AID can often be described in terms of 'the enemy within,' Aladjem's narrative certainly gives a glimpse of the kind of environment that makes this militarization of the body possible. Leaving her home town of Sofia, Bulgaria at twenty-three years old, on 3 March 1941, she notes: "The Germans had been in the country only for a few hours. I could not adjust to seeing so many young men carrying guns and pistols, objects reflecting hatred and savagery. The cold, icy expressions on their soldier faces drained of humor and passion, even of cruelty, made them seem like phantoms walking in the semidarkness" (78). Once in America this atmosphere of military siege persists, although this time in the context of her developing illness; she describes herself as needing "extra ammunition for the battle ahead" (62), and at one point own of her numerous doctor's remarks that "Nature, when she turns against you is a strong enemy," then proceeds to cast himself in the role of military commander - "The doctor searches for allies. He first looks to the patient" (118).

It is interesting and perplexing to note how the doctor and the patient portray their relationship in terms of fighting in the same battle against an enemy other called 'Nature,' when we are talking about a cellular response inside the patient. This linguistic dissociation of patient from disease becomes especially contradictory when for diagnostic purposes medicine must dissect the patient in its search for answers: "These inquisitive young men tried to palpate my spleen, liver, and kidneys with vigorous strength, as if the secret of my affliction could be found buried in the folds of my flesh" (62). Thus disease appears to be both inside and outside the patient simultaneously, making the patient's role unclear, since she's supposed to be looking for, helping to defeat (because naturally she is incapable of defeating the illness on her own), and surrendering the illness to medical authority all at the same time.

This latter implication of the patient harboring the illness, or at least the cause of the illness - as though it were a fugitive in her home - is particularly consistent both with the Cold War political climate and the view that AID is an enemy within. In the introduction, David McCord[21] refers to SLE as "an illness of the most devious and insidious nature - an imposter of a million disguises" (xv), after having described Aladjem as "on trial in a fateful hour" (xiii). One possible implication of these statements is that the patient is literally on trial, in the witness box, having to answer for herself, or at least for her illness, which amounts to the same thing since the illness cannot answer for itself. In this scenario "the doctor assumes the role of a detective" (Aladjem 34), the

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[21] One can speculate about the purpose of having *someone else* introduce Aladjem and *her* narrative to the reader. My feeling is that a strong, masculine introductory voice lends Aladjem a certain credibility that either she, or more likely the editor, felt was lacking and needed (McCord is a poet, historian, and also a trustee at Peter Bent Brigham Hospital).

symptoms like clues in a murder mystery: "Blood was drawn until no more veins could be raised. Bone marrow was taken from my hip as well as from my chest. An elimination diet was instituted to determine any possible food allergies. The search for clues continues" (47). And with SLE the drugs themselves may be a kind of 'truth serum,' since many patients exhibit extreme drug hypersensitivity: "I had no idea that his prescription for sulfonamide might unmask for the second time a disease which I was harboring in my system"(8). But again, what role does this cast the patient in, since what is being sought is not even any known 'foreign' pathogen, but aberrant cellular behavior?

Throughout the entire narrative we keep returning to the search for the "LE cell" which will conclusively prove the diagnosis - "Some of the white cells, have large bluish lumps inside them. We call these cells LE cells" (38) (which, incidentally, is never conclusively found in Aladjem's case). Is the patient still 'innocent' in all of this when the culprit sought is inside them? Are the patient and doctor still allies when the patient is incapable of simply handing over the LE cell needed to validate the doctor's faith in his science? Patient innocence is thrown into doubt when the doctor himself tells a colleague, "Don't let her deceive you" when the other remarks that the patient "looks good" (69). The implication here is that the patient herself is "an imposter of a million disguises," looking healthy when known to be one of the chronically ill. This is also highly reminiscent of Nadler's remark about the beauty of the children harboring abhorrent cancer cells: as Nadler is shown pictures of "the beautiful children" Finklestein has treated he states that he "can't help superimposing images and growth patterns of tumor cells, visually linking children with their harbored tumors" (Nadler 514).

Sontag's opening remark - "Ilness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick" (3) - is also particularly apt here since Aladjem herself is a foreigner in America during a time when foreignness (especially the Eastern European kind) is highly suspect. The deceptive and mysterious nature of the illness is seen as a reflection of the patient's own deceptive nature. Interestingly, Aladjem incorporates into the narrative an incident when, running late for an appointment, she decides to park illegally, remarking to the angry police attendant, "I have never broken the law before in all the sixteen years I have been driving," to which he replies, "Oh, yes, you have [...]. It's just that no one ever caught you" (45). Since there is purpose in every word an author writes, one can muse upon whether the telling of this incident is the patient's attempt to assert her innocence in the face of relentless medical scrutiny. The way the incident is portrayed heightens the sense of injustice at letting the outward actions decide inner personality - much like 'outward' disease is not indicative of inner nature; Aladjem appears to be saying that although her body has broken the law, she herself is not a criminal. Thus, despite her husband's remonstrance of, "You don't owe an explanation to anybody. So there" (29), perhaps this narrative is precisely that.

Despite periodic expert reassurance that 'they' are in this fight together against some foreign enemy other that is not part of the patient's self, there is still the conflation of disease with patient selfhood. Maintaining the separation of disease and self is made even more difficult when Aladjem is told that SLE may be a result of damage to DNA, "a vital constituent of every cell. It is the genetic substance, the identity of the cell" (69).

What happens then when the 'culprit' is discovered? When the culprit is your own immune system, supposedly attacking your very identity, is it even possible to tease out what does not belong, and then actually remove it without removing the whole patient? To all initial appearances Aladjem is able to maintain this mental separation of mind and body: "the only way to correct my kidney condition was to eliminate the insulting agent" (64); "It is reasonable to hope that everything will clear up if we remove the source of the trouble" (73). In this instance there is definitely the impression that the disease is not considered a valid part of Aladjem's life experience, and that her life will somehow resume only with health: "How could I have known that day that a few years later my rare and little-known disease would be arrested, and I would again be able to enjoy an active life" (1)."

Part of the difficulty with simply accepting the disease as part of self, however, may be that with many autoimmune diseases (especially in these early days of immunology research) a diagnosis, much less a concrete cause, can be difficult to obtain: "I was unaware of how ignorant the medical world was about this devilish disease" (Aladjem 12). Even after 20 years of expert poking and prodding, Aladjem is still unable to get a definitive answer, and then the disease disappears. Confounding initial attempts at a diagnosis, the body itself appears to play a cat and mouse game with medical expertise, further positing the patient as deceptive: "I tried to explain this new development to Dr. Fried, but each time I made an appointment, by the time I kept it, the lumps had disappeared. It was very embarrassing; [...] That day I left his office feeling more than foolish. Was I losing my mind?" (14). Because medical expertise is unable to name and validate the disease, and the patient does not have enough confidence in her own experience of her body, she is furthermore thrust in the role of hysteric: "I am afraid I've panicked" (31), "I feel like a hypochondriac whenever I talk about it" (74).

Similar to Charlotte Perkins Gilman's narrative *The Yellow Wallpaper* (1892)[22] - where the heroine eventually performs the madwoman role she has been assigned by the medical establishment (represented by her doctor husband) - Aladjem also momentarily questions her sanity:

> During this time, my system began to retain fluids and I felt dizzy. The radiators in our house were the old-fashioned kind - painted a bright silver - and if I looked at them for very long, their shape appeared distorted. The same would occur with the geometric design of silver and gold in the wallpaper. The bizarre floating sensation and difficulty in focusing seemed like an hallucination. I could not bring myself to mention the radiators or wallpaper to anyone. (28)

Considering that this excerpt is then followed by the repetitive mantra, "I know that I am not crazy" (28), the fact that Aladjem does mention the radiators and wallpaper now, to potentially countless strangers, makes it more likely that she is seeking to finally validate her sanity through narration. By writing the story of her body, her suffering, her numerous, unacknowledged symptoms, she also subverts one doctor's warning (issued as

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[22] In Perkins' text the wallpaper is described as "a smouldering unclean yellow;" "dull enough to confuse the eye in following, pronounced enough to constantly irritate and provoke study, and when you follow the lame uncertain curves for a little distance they suddenly commit suicide--plunge off at outrageous angles, destroy themselves in unheard of contradictions." The traditional power imbalance between a female patient and her doctor is made poignantly clear when Gilman's protagonist laments: "If a physician of high standing, and one's own husband, assures friends and relatives that there is really nothing the matter with one but temporary nervous depression--a slight hysterical tendency--what is one to do?" (Garcia, Viola. *The Yellow Wallpaper*. < http://itech.fgcu.edu/faculty/wohlpart/alra/gilman.htm#INSERT%203>).

she is "lying in bed feeling like a deflated balloon,[23] even too weak to speak" (88)) that she "must be careful not to become a chronic complainer" (88), and gives herself permission to 'complain' for 150 pages. The indignation that she feels at the implication that her symptoms are "psychoneurotic" perhaps gives her the strength to reclaim her weakened voice through this narration.

In fact, all throughout the text reference is made to the importance of voice, bringing us back again to the centrality of communication in the experience of illness. From the moment Aladjem experiences the first symptoms of SLE, her voice is also affected: "I could not find breath to utter a sound. Eventually, I managed to whisper that something seemed to have happened to my voice" (4). Remembering how as a child in Bulgaria she was encouraged to keep "Les mains croisées et la bouche fermeé" (hands crossed and mouth closed), she notes how "Both requests were torture" (95). And now medical expertise is similarly intimidating her into silence; there is repeated reference to expertise objectifying and talking through the patient, again, despite the claims to egalitarian war-time comraderie, as observed by the very first sentence of the narrative: "'Your patient doesn't have a chance. Her last LE prep was positive. Her kidneys have collapsed sixty percent. What more evidence do you need?' The authoritarian voice with a sonorous Harvard accent sounded nightmarish behind the door of my hospital room" (1). Talking through the patient thus also implies not just talking through her (or more accurately, through her symptoms), but talking to other experts through the patient.

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[23] Although the expression "deflated balloon" generally denotes lagging spirits, in this instance I cannot help thinking that it also represents useless femininity: the sick woman is also (in typical cultural renditions) an undesirable, asexual, and barren woman - as Nancy Mairs notes: "Most people, in fact, deal with the discomfort and even distaste that a misshapen body arouses by dissociating that body from sexuality in reverie and practice" (51); what also remains deflated inside the sick woman is the womb.

Reminiscent of a Sedgwick triangle where the feminine represents one point on a triangle and is the medium by which the two males occupying the other positions relate to one another, with the bond that links the two males being "as intense and potent as the bond that links either of the rivals to the beloved" (Sedgwick 21),[24] medical doctors also appear to use the now identity-less (where selfhood has been seemingly removed from the 'petri dish') female body to converse with one another. Advised by a doctor that "sounded for a moment as if he were talking to a child" that it would be "foolish" for her to manage her condition by herself, Aladjem is told she needs "a skillful man who will become interested in [her] case and be willing to spend lots of time on it" (39). Highly reminiscent of B cells needing help from masculinized T cells to perform their functions, this arrangement similarly makes the important interactions occur between male experts: "It was obvious that they were talking about me, but for some reason had not muted their voices" (63); "Dr. Gardner never missed an opportunity to listen to another opinion from an authoritative colleague" (67); "Dr. Gardner reported periodically to Dr. Thorn and Dr. Diamond about my progress. The diagnosis, for my ears, was 'leukopenia'" (52). This latter statement in particular implies that the nature of the communication between the experts is vastly different than that between the patient and expert - again, using the

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[24] Sedgwick bases her argument in the idea of a continuum of 'homosocial desire,' the term referring to "social bonds between persons of the same sex" (1), and in the case of males specifically (at least in most present cultures), marked by "intense homophobia, fear and hatred of homsexuality" (1). Thus, although male homosocial desire denotes 'men promoting the interests of men,' (or, "relations between men, which have a material base, and which, though hierarchical, establish or create interdependence and solidarity among men that enable them to dominate women" (qtd. in Sedgwick 3) - and hence why I believe it relevant to my discussion of the female patient's relationship with her doctors), it does not necessarily contain an erotic component.

immunology equivalent, B - T cell interactions are called 'help,' whereas T - APC interactions are termed 'co-stimulation.'

Another reason why I described the patient as self-less, is because the communication between experts occurs in the specialized language of symptoms, where the patient literally becomes unpronouncable words and indecipherable numbers on endless charts, rather than a whole being: "Your hematocrit is forty-three, hemoglobin thirteen-point-four, white count four-three four-oh, polys twenty-nine, lymphs twenty-one, BUN eleven, uric acid four-point-eight, sedimentation rate twenty-two" (60). At one point, when Aladjem's test results return, the doctor - glancing only briefly in her direction - proceeds to discuss them with the group of experts gathered by her bedside - "the EKG, chest film, GI series and IVP were normal" (48). Supposedly "absorbing every word" (39), the patient then attempts to speak the same expert language in an attempt at inclusion in the conversation. It is interesting that a narrative written by a patient sounds as technical as most medical textbooks I have read. Interestingly, whenever medical terminology is used in the narrative, it is usually followed by symbols leading the reader to the bottom of the page where there is a more detailed, lay-person translation. In this way the patient-author finally becomes one of the experts, a full participant in the story of her body as told through symptoms: "'That's the only way you'll become a member of the team,' he said, then added, 'patient participation based on sound medical information can be of much help to the doctor'" (Aladjem 46).

The fact that the patient can be dissected into bits and parts adds another dimension to the need for active verbal inclusion in expert conversation - because parts can be removed and isolated for testing, it seems even more that everyone but the patient, including the patient's own body, can speak this expert language. Because the body generates numbers whose significance is invented and only understood by expertise, it as well appears to be conversing with expertise behind the patient's back. This is especially true because most data analysis occurs in places like Nadler's laboratory - seated comfortably on the glass couch, the cells divulge all their secrets to the technician, while the patient, pacing their living-room, wonders what will be said: "Dr. Gardner's sending my blood to the Rockefeller Institute marked the beginning of a long period of having my blood sent many more times to New York City, Los Angeles, California, and down east to Waterville, Maine" (67). Aladjem's remark that 'for her ears, the diagnosis is leukopenia,' becomes even more significant if her cells are whispering in the ears of experts, and they in turn whisper to each other, and only then carefully select what to tell her. What this ultimately implies is that the patient is incapable of hearing and understanding her own body, and most importantly for the medical profession, needs expert help to do so.

Because the patient is trained to converse with medical personnel only in the language of symptoms, interactions with other patients are similarly limited: "Jordan was reluctant to speak of his illness. Only after he understood my predicament did he open up. We began to compare notes. Most of the symptoms I mentioned, he had also experienced" (75). And rather than it being a simple, direct interaction, the patients also feel the need to mediate their exchange through a medical expert: "He suggested that I write to his sister, a physician in Bulgaria, to find out more details of his medical history.

He thought Dr. Gardner might find it of value to know if his condition were clinically similar to mine" (77). Convinced that only medical expertise knows the full story of their body, the patients in this narrative, rather than communicating with one another and using each other as direct sources of information, adhere to their isolation; in a moment of extreme loneliness Aladjem begins speaking to herself, and sympathizes with the old woman talking to birds: "Why would anyone talk to birds? I wondered. Perhaps she was lonely, I speculated. Perhaps the birds did not intimidate her" (98).

In the thirty years since the publication of Aladjem's story (and nearly fifty years after the beginning of her struggle with medical expertise), we have had Oprah and Dr. Phil, a parade of self-help books aspiring to facilitate communication of every genre, support groups sprouting all over the place like dandelions, and of course, the internet. At the same time, however, we have also seen the field of immunology explode into innumerable, even more specialized sub-fields. It appears that with the frenzied, industry-driven pace of medical research the patient simply cannot keep up, and is just as (if not more so) unable to communicate in the expert's language - which may to some extent explain the recent popularity of the talk show, the support group, and the illness narrative. And although turning to other patients and caregivers for support seems more acceptable now than it did fifty years ago, illness can still be a profoundly isolating experience. Ironically, part of the reason for this isolation may be precisely *because* rapid advances in biomedical research have made many complex and mysterious diseases more readily diagnosable; stigmatization of the ill begins with the naming of the disease.

In many ways Aladjem's narrative exemplifies Frank's definition of the *modern* experience of illness - "when popular experience is overtaken by technical expertise, including complex organizations of treatment," and "being sick is surrendering oneself to the care of a physician" (Frank 5). Advances in medicine and immunology mid-twentieth-century meant that rather than 'going to bed and dying quietly' people began going "to paid professionals who reinterpret[ed] their pains as symptoms, using specialized language that [was] unfamiliar and overwhelming" (Frank 5). Therefore, in the modern experience of illness "the chart becomes the official story of the illness," and the physician's story "becomes the one against which others are ultimately judged true or false, useful or not" (Frank 5).

In contrast, "The *postmodern* experience of illness begins when ill people recognize that more is involved in their experiences than the medical story can tell" (Frank 6). Most importantly, the shift from premodern to modern, and from modern to postmodern involves issues of *voice*; although the modern patient is assailed by medical terminology that leaves her bewildered and silent, she "does not perceive a need for what would now be called *her own voice*, a personal voice telling what illness has imposed on her and seeking to define for herself a new place in the world" (Frank 7). In crossing the modern-postmodern divide, however, there is a "need for a voice [patients] can recognize as their own" (Frank 7). Interestingly, Frank proposes that this need for expression depends on "the availability of the means - the rhetorical tools and cultural legitimacy" (7), which sets up the classic 'chicken and the egg' dilemma: does the availability of the means for a certain kind of expression give rise to the desire to express oneself in that way? Or, does the desire for a different kind of expression create the venue? I believe it is in fact more of the latter, but ultimately a complex interplay of these two scenarios that contributes towards a change in how and what we communicate. Thus, one can argue that it was not the sudden emergence of talk shows, support groups, and personal tales of adversity and triumph that legitimized and created a need for the intimate narrative, but rather that the collective desire to share one's life experience inspired the creation of these venues. The next question, of course, is how and especially *why* this need to share oneself with others in a non-institutionalized form arose to begin with. Although I do not want to discuss this at any length (it is a thesis onto itself), suffice it to say that I believe the fast-paced, image-based, and materialistic nature of modern industrial life has contributed to widespread feelings of alienation (ironically, considering how 'connected' we are said to be). The personal illness narrative is therefore an attempt to situate the alienated and isolated body in a communal context.

In her narrative on MS, *Waist-High in the World: A Life Among the Nondisabled* (1996), Nancy Mairs notes how:

> In a society that prates about, but seldom practices, communication, the craving to be listened to, heard, understood - which originates with the first terrified wail, the circling arms, the breast, the consolatory murmur - is hard to assuage. And because a cripple, in order to earn a shot at social intercourse with 'normals,' must never publicly lament her state, must preferably never even mention it, an other who treats disability as a safe topic of conversation offers immeasurable relief" (7).

This particular comment comes after a complete stranger, after reading one of Mairs essays on disability, contacts her, explaining that it feels "so much better just talking about MS. Maybe I could call again?" (5). Acknowledging the fear and isolation this young woman must be feeling, Mairs then goes on to admit: "Like Jennifer, I often need no more than someone to whom I can speak frankly about MS without being dismissed as a whiner (a distancing tactic often practiced by those in whom disability triggers unbearable anxiety)" (7). Of the several issues raised in these passages, the fear of being perceived a 'whiner' for wanting to discuss illness seems, still, the most imperative.

Despite the progress made in diagnostic technology - "MS-specific neurological tests, CAT scans, and MRIs, and all he could do" (Mairs 27) - aimed at reading the body much better, MS (and most autoimmune diseases) still remains a difficult disease to definitively diagnose. Because of this there is still the tendency to regard patients (especially female patients) with medically difficult to read bodies as 'hysterics.' Reiterating again the importance of 'naming the rose,' the diagnosis can offer relief simply because the trauma of *not* having this very real but subjective physical experience acknowledged by collective language is even worse: "My disease manifested itself clearly enough so that the doctors didn't dismiss me as an hysteric or a malingerer, the lot endured, sometimes for years, by many with MS, especially those with the milder, relapsing-remitting form" (Mairs 28). What this ultimately points to is the power of language to include the individual, and the individual desire to be included, in a larger whole. What is it about having your (physical) existence represented by language? Is it that so much of our life and interaction with the other is enmeshed in words that not being able to represent your body in words almost means that it is not there, at least on a certain level? Is it because, as a "distancing tactic," our culture would rather not talk about illness, thus truly isolating the patient from the "normals" like an 'LE cell' on a microscope slide?

In a rather desperate attempt to finally have her body read and named by medical expertise, to prove its corporeality, Aladjem risks severe bodily trauma: "A morbid thought occurred to me. Should I expose myself once again to the sun to prove my light sensitivity? The following weekend when my husband and I drove to Maine to visit some friends, I held my bare arm out the window for over two hours to the mercy of the sun and the wind. The following day, big red angry welts erupted on my skin. The spots didn't fade for months" (109). What the outward physical manifestation of disease symbolizes is, of course, inward disease that was previously a reality only to the patient - "some of the symptoms are just at the surface or just below the surface and occasionally, under fatigue or stress, for example, can rise to the surface and be perceived" (Risidore 60). With the sunburn Aladjem has made her body 'readable' and thus moved it into the 'real' realm of language.

Similarly, in *Multiple Sclerosis: The Kinder Side*, Lyn Risidore echoes the need to have expertise "confirm" illness "by saying, 'I can positively say you have MS.' [...] even though MS symptoms are obvious to [the patient]" (17). Adhering to the medically prescribed military metaphor of illness, Risidore goes on to add that the "peace of mind that comes with the acceptance of the resignation of the disease" is due to the fact that "A known enemy is easier to face than a hidden one" (17). Knowing that the variability and transience of MS symptoms can often make the patient appear deceptive, clearly readable exterior symptoms are also desirable because they create an other of disease against which all of society must 'do battle.' In the section written by Isidore's neurologist, Dr. R.J. Duke warns that "When dealing with your doctors, remember that they cannot read your mind. I think it is important to be open with no 'hidden agendas'" (58). Naming the enemy as the other of disease (even when there is no known invading pathogenic other as in autoimmune disease) ensures that negative traits associated with treachery - which the female patient may be especially susceptible to[25] - finally become displaced from the patient onto the disease itself. In this way the patient is allowed to rejoin 'the team' in the common fight against this enemy. But again, it gets really tricky to maintain this clear delineation between person and disease when this supposed other is a type of cell inseparable (in its totality) from the body. Even while stressing that MS is "an illness that is not going to be eliminated by taking the right pills or following the doctor's advice," Duke then still posits the condition as "this enemy" other (53).

Maintaining the mental separation of disease and personhood, while medicine attempts to actually separate the disease from the person, can lead to a sort of existential crisis for the AID patient: the former implies a "Cartesian construction of [*an already*] separated mind and body" (Stacey 101), while the latter implies a *union* of body and mind that must subsequently be severed by a medical 'cure.' In the case of autoimmune disease this equation becomes even more complex: because the offending other is actually also self, the body must first be separated from the body before the body can be

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[25] Throughout history "Female bodies, even handsome and wholesome ones, have tended to give moralists fits of one sort or another" (In *Malleus Maleficarum* it is stated that "All witchcraft comes from carnal Lust which is in Women insatiable") (Mairs 58); the fact that women are as much as ten times more likely to develop some autoimmune diseases than men only makes them further susceptible to the kind of ancient stereotyping that equates femininity with a treacherous, uncontrollable, body.

separated from the mind. Ironically, the experience of illness may be needed to heighten one's awareness of the inseparability of body and mind to then want their separation:

> The physical processes of a perfectly healthy person may impinge so little on her sense of well being that she may believe herself separate from and even in control of them. From here it's a short leap to the conviction that cerebral phenomena are of a different, generally higher, order than other bodily events and thus possess transcendent and even immortal qualities, at which point the imagined mind becomes the even more fantastic soul. (Mairs 41)

In other words, the separation of body and mind that ill patients are encouraged to maintain is most readily possible during *health*, when the body can effectively be ignored. While in illness the dis-eased body continually impinges on the workings of the mind - when the body is in pain the mind can think of little else (mostly because pain must be thought into existence - the mind cannot deny the innumerable electrical impulses clamoring for mental translation), therefore asserting their connectedness, and wanting even more their separation: "Myelin dissolves, nerves short out, muscle atrophies, but the old brain, riddled now with sclerotic patches, goes on wailing, 'I can do it myself'" (Mairs 70).

Because the practice of medicine currently does posit disease, even autoimmune disease, as something that *can* ultimately be separated from personhood, it therefore also implies that while the two remain attached the life lived is not a legitimate one: "I now carried this thing inside my body like an unwanted guest and I was unable to do what I wanted. Life was not proceeding according to my plan. I knew I had to find the self I had lost if I was to have a life of value" (Risidore 30). The ill self is therefore not a legitimate self. What this passage also implies is that illness can disrupt the imagined linearity of one's life. By bringing one's attention so forcefully to the physical, illness also brings one more fully into the present, making it difficult to project oneself as easily into the future or the past (since the knowledge of present illness also makes the patient re-evaluate the past differently): "How could I have known that day that a few years later my rare and little-known disease would be arrested, and I would again be able to enjoy an active life" (Aladjem 1). The ill life is therefore not only an illegitimate life, but also a life on hold.

In *The Wounded Storyteller* Arthur W. Frank also notes the importance of "a sense of temporality" in storytelling (55). The imagined self that stars as the main character in the mental movie version of one's life - with "a past that leads into a present that sets in place a foreseeable future" (dramatic music, great costuming, guaranteed tragic ending) - is disrupted by illness: "The illness story is wrecked because its present is not what the past was supposed to lead up to, and the future is scarcely thinkable" (Frank 55). As Risidore admits, "Life was not proceeding according to my plan." Aladjem's description of a post World War II Rotterdam is an especially apt metaphor to describe this: "the city of Rotterdam lay in ruins. The center of town was totally razed, like a metropolis without a heart. Odd remnants of walls stood here and there, preserved for future use" (2). Likewise, the life on hold implies a disease-ravaged body with some semblance of external integrity 'preserved for future use.'

It is interesting to muse whether in perfect health the Cartesian separation of body and mind is more feasible because unless the body calls attention to itself life occurs mostly in the Hollywood of the mind. With illness, however, the discrepancy between the actual physical life and the imagined movie life is too great to be effectively ignored - simply going on with the imagined life thus also becomes too difficult. The lost self that Risidore must find in order "to have a life of value" can therefore be referring more to the imagined self, since what has primarily been lost is a certain *image* of the self, (or of what the self *could* be with a little work), rather than the self per se. As Mairs notes, "Even in the fifties, before the dazzle of shopping malls and the soft pornography of advertising for every product from fragrance to bed linen, a girl learned to compare herself unfavorably to an ideal flashed at her on glossy magazine covers and cinema screens" (44). And when the body is too weak and uncoordinated to put on lipstick, that Hollywood self is no longer even an imagined possibility. So what would it take for the physical experience of illness, when (not if) it occurs, to be simply incorporated into the imagined narrative of one's life as just another experience, without obliterating the imagined self? And if it is possible to incorporate illness into selfhood, then how does contemporary medicine's perpetual attempt to separate the two affect this self?

Beginning with the admission that her experiences as an MS patient marks hers "as an undesirable, perhaps even an unlivable, life" (4), Mairs then spends the remainder of the narrative examining how the experience of MS has affected her identity, and especially, what would it mean to be 'MS-free.' When asked one day by a friend, "But Nancy, who would you be if you didn't have MS?" - after having lamented about "the ways in which MS was cramping and skewing [her] life" - Mairs contemplates to what extent MS *has* become a part of her identity:

> Who would I be if I didn't have MS? Literally, no body. I am not 'Nancy + MS,' and no simple subtraction can render me whole. Nor do I contain MS, like a tumor that might be sliced out if only I could find a surgeon brave and deft enough to operate. Physiologically, lesions - sclerotic patches, or plaque, where the nerve sheath has been destroyed and scar tissue has formed in its place - have appeared throughout my brain and spinal cord: they are integrated into my central nervous system just as thoroughly as the remaining healthy tissue. Since they can be located with Magnetic Resonance Imaging, I suppose they might be cut away, but what remained would be an even less serviceable version of a 'Nancy' than the one MS has fabricated. (Mairs 8)

The notion that without MS Mairs would be 'no body' is especially interesting here in light of the statement that health in a sense obliterates the body. The implication is that without a debilitating illness to continually bring her back into corporeality her body would disappear. The other implication, of course, is that her experience of MS has now become such an integral part of Mairs's identity, that isolating, removing, and discarding a moment now belonging to the past would render identity even more fragmented and problematic, rather than restoring her to selfhood.

It is interesting how in the span of this quotation Mairs moves from the common notion of illness as making the patient somehow less whole - and that its subtraction renders the person once again whole - to the possibility that illness in fact adds to one's identity like any other life event, and that its removal entails another readjustment of imagined selfhood. Restoration post-illness to a previous, healthy mental version of selfhood is thus unrealistic - unless the now well patient is willing and able to completely forget the experience.

Particularly effective is the description of what is happening at the physiological level. Imagining the separation from 'disease' reified is much easier when the disease is precisely that, a thing, other, the enemy. But when the disease is a bodily process like demyelination and fibrosis that requires the complex orchestration of the immune system, tissues, nerves, signaling molecules, and genes within the nuclei of cells (by no means even close to an exhaustive list!), separation and post-operative 'wholeness' begin to look nonsensical.

The fact that Mairs chooses not to mention either 'autoimmunity' or 'autoreactive T-cells' in the description of her illness, even though she is well aware of the terms, demonstrates her sensitivity towards the language of disease. A possible explanation for this omission is that the semantics of autoimmunity succumbs too easily to military analogy and the othering of both illness and the body. Accepting the idea that "the immune system apparently begins to 'think' of the myelin, the fatty substance that sheaths the nerves, as an alien invader to be destroyed" (Mairs 28) - in other words, "a chronic civil war within the body" (qtd. in Aladjem 23) - potentially entails accepting the idea that the body does not want itself. Or, in the least, that something does not belong - whether that be the wayward immune system itself, the myelin sheath around nerves, the plaques in the brain ("This time there's something in the right side of your brain that doesn't belong there" (Mairs 25)), the resulting symptoms experienced, or the life being lived. How far of a leap is it from the potentially inexhaustible list of all the body parts that do not belong in this scenario, to thinking that the whole 'thing,' the patient herself, does not belong?

Remarking how for years after the onset of MS symptoms she "used language to avoid owning them" such as "The left hand doesn't work anymore," or "There's a blurred spot in the right eye," Mairs notes that such distancing, although it may momentarily keep grief at bay, also banishes "any possibility of self-love" (43). Instead, she gradually schools herself to say "'my' hand, 'my' eyes, thereby taking responsibility for them" (43). Perhaps taking ownership of the "afflicted body" would be infinitely easier if we thought of ourselves as "simply [...] a creature that suffers, as all creatures suffer from time to time. Rather, it is thought to be 'broken,' and thus to have lost its original usefulness; or 'embattled,' and thus in need of militaristic response, its own or someone else's" (Mairs 47).

The repeated references to the uselessness of the diseased, disabled body are especially significant here because, just as cells not adhering to their idealized roles are described as useless by some immunologists (remember Nadler's characterization of malignant cells as "confluent clusters with nothing to show for their growth but the senseless occupation of marrow space," "bumbling rather than brutal creatures, unable to be of service, to benefit a single other living cell"), the useless body can similarly be thought of as indicative of a greater non-utility. The patient herself becomes useless in all the ways society deems important:

> Good for nothing. I mean really. I can stand with assistance but I can't take a step; I can't even spread my own legs for sex anymore. My left arm doesn't work at all, and my right one grows weaker almost by the day. I am having more and more trouble raising a fork or a cup to my lips. (It is possible, I've discovered, though decidedly odd, to drink even coffee and beer through a straw.) I can no

> longer drive. I lack the stamina to go out to work. If I live to see them, I will never hold my own grandchildren. (Mairs 61)

The efforts of science to remove inept cells from the body can thus bear directly on how the patient imagines herself relating to the rest of society. Disability due to illness seems to warrant and sanction the removal of the *patient* "from normal life into a 'discredited' position in relation to society" (Mairs 61) - "Better to deny the perfectly ordinary qualities most cripples possess, thus ascribing to them an other, safely remote reality, than to risk identification of their own lives with a life that dismays and perhaps even disgusts them (Mairs 32).

Much like with the immune system, what the diseased body demonstrates is that utility and competence are largely context-based. One of the things that progressive disability allows is utility to be continually recontextualized: "The bare rehearsal of my progressive disability conceals an increasingly intricate set of exercises in problem-solving that have kept me on my toes (even though off my feet)"[26] (Mairs 33). The "sort of attention, resourcefulness, and adaptability" (33) that Mairs describes is also highly reminiscent of how the body is described in the context-based models of immunity. What we all do throughout our lifetime, but that becomes especially apparent with disability due to illness, is minimize disaster to the best of our physical abilities: the baby who cannot walk stumbles along on hands and knees, the graduate student who has

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[26] "What to do when sacks of groceries became too heavy to carry? Ask the clerk to pack more of them with fewer items. What to do when I got too weak to carry them at all? Buy a little four-wheeled wire cart. What to do when I could no longer push the cart? Request that someone else carry them to the car. What to do when I could no longer drive to the market in the first place? Have George take me. What if George should get too busy or ill? Reserve a ride on Van Tran; the driver will carry my parcels into the house. What if I no longer have the strength to put my own groceries away or to go out at all? Hire a shopping service" (Mairs 33) - an example in disaster-minimization.

thrown her back out by sitting at the computer too long props herself up on pillows, the arthritic elder takes his time getting down the stairs. If utility were based solely on perfect health, then virtually all of us would be considered useless.

Because utility is culturally prescribed, as Barbara Webster notes in *All of a Piece*, accepting the diseased body as good and useful thus also necessitates rejection of the cultural value system: "I can accept the disease or I can accept the dominant values of this society; I doubt it is possible to do both" (Webster 85). In this way the seeds of patient rebellion begin to mature. Either way, however, the society can still, and often does reject the patient from its metaphysical plasma for fear of their influence on the well being of the whole. Perhaps then, disinheritance of one's own body (by agreeing that one's diseased body is indeed invalid and must be rejected) is a means of regaining entrance into the social plasma by seeming to accept its value system through the rejection of what it deems undesirable. Continued belonging is provisional though on the grounds that the patient continues to reject the disease and to divide the 'heroic' from the 'defeatist.'[27] Acceptance of the disease as a human variant, "the consequence of cosmic bad luck," rather than a deviation "from the fully human condition, brought on by personal failing or by divine judgment" (Mairs 47), thus also necessitates the rejection of not only the cultural value system, but the imagined self that was born of it: "The 'her' I never was and am not now and never will become. In order to function as the body I am,

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[27] Often among the newly diagnosed there is an attempt to mentally and physically distance oneself from other patients that appear to have stopped 'fighting' or that appear sicker than oneself. Mairs confesses that if she found herself in the company of others with disabilities she "was aware of being different from them, with their tremors, their slurred speech, their wandering eyes, their walkers and wheelchairs and leg bags"; labeling these other others as "them" is therefore a distancing tactic and a sign of alignment with the healthy others.

I must foreswear her, seductive though she may be, or make myself mad with self-loathing" (Mairs 47).

But just because the patient has rejected the culture that has rejected her, does not mean that she will stop longing for inclusion into a larger whole and cease attempting to reshape culture from her banished position; as 'maddening' as the other may be, they are integral to the experience of living: "I doubt that any body, whether in trouble or out, can fully conceive a self without an other to stroke it - with fingertips and lips, with words and laughter - into being and well-being. Research has demonstrated that infants deprived of touch fail to thrive" (Mairs 49). As much as private acceptance of one's diseased body helps in the mental construction of an integrated selfhood, it is intimate reciprocal interaction with the other that makes the patient 'more than the sum of bodily problems' (Mairs 55). This is also why context-based models of immunity that focus on communication may better explain the actual experience of illness, since they posit disease as *defined by* the nature of the interactions between immune components and entering entities: again, *there can be no disease* without interaction. Ultimately, the goal of such explanations should be to provide an idea of the body that is in tune with changing notions of what constitutes reality, and especially what our role within it is.

The illness narrative can thus serve as both an attempt at re-entrance into the social 'plasma,' and a critique of its properties to make belonging less problematic if it occurs. The act of writing itself can be seen as a demonstration of continued societal usefulness. Since "Doing is highly valued in American culture and doing, as opposed to being, is a primary response to almost anything" (Webster 69), writing still constitutes 'doing': "In other words, what I can still do - so far - is write books" (Mairs 63). Sensing that "The world as it is currently constructed does not especially want - and plainly does not need - [her] in it" (87), Mairs thus uses "inscription to insert [her] embodied self into a world with which, over time, [she] [has] less and less in common" (63). By reading the narratives the rest of society is made complicit in the patient's reentrance into the plasma - Nancy Mairs, Barbara Webster, Henrietta Aladjem, Lyn Risidore are all now part of our 'selves': "Our bodies conceptualize not only themselves but also each other, murmuring: Yes, you are there; yes, you are you" (Mairs 50). In a sense the illness narrative is like Aladjem's sunburn - invisible, internal suffering converted into an exterior symbol of pain for all to read. I have often wondered, having repeatedly witnessed ageing relatives' solicitations of sympathy for their painful bodies, why we so desperately need our pain to be acknowledged by others? Is it because pain is ultimately such a personal experience (pain literally needs to be thought into existence by the individual mind), therefore reminding us that life is a kind of solitary confinement within body and mind? Are attempts to share this pain, to make it real in a grander collective sense by inspiring others to also think about it, ultimately attempts at joining isolated bodies together, much as in sexual contact?

In summary, the aim of this final chapter was to demonstrate how the personal experience of illness is shaped by every aspect of biomedicine and the culture in which it is practiced. In particular I wanted to draw attention to how the fragmentation of the body in basic research and medicine does impact personal conceptions of the body and self. If individual particles in a plasma have the ability, through communication, to influence the behavior of the others, then illness narratives like Mairs' that subvert prescribed patient thought and behavior might also affect greater notions of illness in society. One of the reasons I find Matzinger and the DM so fascinating is that like one of the "toon characters in the movie, Who Framed Roger Rabbit? - obviously beholden to their creators, but fiercely independent in pursuing their own destiny as determined by their individual characters. She too has been written into a story, but has taken it in a direction very much at odds from that intended by the original authors" (Tauber 246, 2000). Thus the patient also, as demonstrated by Mairs' narrative, has the ability to take her story in a direction potentially at odds with the medical profession's.

Conclusion:

Based on the amount of revenue generated by the pharmaceutical industry every year, the increase in direct to 'consumer' drug advertising, the amount of space increasingly dedicated in news media to illness generally (especially if it lends itself to sensationalism, such as the current 'battle' against SARS and West Nile Virus in Ontario), it is obvious that biomedicine has come to occupy a major role in contemporary Western culture. The field of immunology in particular, due mainly to rapid advances in research technology, now impacts individual lives like never before in history. Unfortunately, the relationship is seldom reciprocal. The massive expansion of the field has guaranteed that knowledge becomes more specialized and thus remains understandable to only a select few, who are then responsible for how that knowledge becomes disseminated among the masses. Biomedicine therefore impacts individual lives, but non-experts rarely have the chance to influence biomedicine.

The problem with this kind of setup in a field like immunology, however - considering that we have cheerfully surrendered so many tasks associated with our survival and comfort into the hands of qualified experts - is that it excludes the individual from the construction of the collective mental image of the human body. The problem with this, in turn - despite perpetual claims to scientific objectivity - is that because the 'mental body' is constructed by experts of a specific gender, class, and even race, power inequalities based on those same factors become inscribed onto the body, and thus naturalized. This is most evident in the paradigms generated to interpret and to describe cellular interactions: the masculinized T cells educated in the thymus university treat other (subordinate) cells in often violent ways, feminized B cells need T cell help in order to fulfill their prescribed role of antibody production, T cell interactions with other masculinized cells like APCs are thought of as 'co-stimulation' rather than 'help,' 'scavenger' cells of immunity such as macrophages are likened to minorities because of the 'blue-collar' association, and non-sanctioned immune interactions are termed 'promiscuous.' In other words, we construct our reality largely based on current social notions of reality.

The widespread use of military terminology in biomedicine in particular demonstrates the mutually reinforcing nature of the systems that construct reality, thereby further naturalizing them. I am positing that the immune system, as it is currently conceived, represents a microcosm of social interaction. And as such, also has the power to influence social interactions to resemble itself and that which it is in turn representing in a kind of complex feedback loop.

When illness is caused by a 'foreign' pathogen the hierarchically organized troops of the immune system 'do battle' to banish the invader from the body. Not surprisingly, an immune system obsessed with self-nonself discrimination was first articulated during the 1950's xenophobic Cold War era. And although the paradigm has served immunologists well enough over the past fifty years to allow for many 'discoveries' to be made, it has also simultaneously restricted research to those experiments that would further validate the paradigm. As a result, many diseases and immune phenomena that challenge the assumptions of the SNS paradigm remain only provisionally explained. Of these the autoimmune-related diseases pose the biggest quandary: why is it that after millions of years of immune evolution a system supposedly ordered on self-nonself discrimination and adherence to strict roles still 'malfunctions' so frequently and 'attacks' self?

Or does it? As Polly Matzinger has demonstrated, our images of immune system competence may be paradigm dependent. And if the guiding principle is minimization of danger, rather than self-non discrimination, then even in cases of autoimmunity the system may still technically be doing 'its job.' Not only does this paradigm shift encourage novel experimental questions and data interpretation, but it may also allow for autoimmunity to be explained in less frightening language to the patient - as a conversation that took place rather than an internal civil war. And as we saw in the preceding three chapters, the *semantics* of illness can critically affect the *experience* of that illness, especially as it pertains to interactions with the other, and with self.

The novelty of Matzinger's Danger Model is not only that it discards the terms 'self' and 'nonself' from immune terminology, but also that it seems to be based on fundamentally different modes of relation. Rejecting the notion of hierarchy among cells, Matzinger 'brings into the conversation every cell in the body,' including previously passive body cells (which can be likened to the passive patient on which a military/medical intervention is done). Proposing that 'immunity is a conversation not a war,' the DM emphasizes the importance of communication among immune cells, tissue cells, and pathogens. The emphasis therefore shifts from fortress-like notions of limited entrance and to a body in constant, intimate contact with its environment - 'because, of course, it's going to be coming in.' And just as how in the SNS paradigm immune interactions reflect and simultaneously promote certain kinds of social interactions, the DM, being based on communication and more egalitarian interactions, thus urges, and reflects the emergence of reflection of, a different ideology at the macro social level.

Matzinger's own promotion of the model among scientists and non-scientists alike is a fitting example of the circular relationship between paradigm and social ideology. Repeatedly Matzinger is shown to urge interdisciplinary communication among those interested in the evolution of the model, welcoming both positive and negative feedback, critiques of the basic research arising from the DM, suggestions for novel experiments, and alternate interpretations of existing data - going so far as to establish a website for such discussion, accessible to anyone and everyone. Such an approach is, of course, like the model itself, aimed ultimately at minimizing disaster rather than maximizing gain. And although they are few and far in between in a society driven by capital gain, there are precedents for such an approach: "The complexity of the real world of technology offers no fundamental barriers for implementing strategies to minimize disaster" (Franklin 85).[28]

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[28] An example featured in Franklin's text is the study *Canada as a Conserver Society*, conducted by the Science Council of Canada (1975). Looking at how Canada could become a society dedicated to the preservation of our environment, "The realization of the urgent need to minimize disasters became embedded in all phases of the study" (Franklin 86). Not only was this "reflected in the research questions asked," but "From the beginning of the investigation the communities of concern, ranging from citizen groups to regulators and industry, were drawn into the process" (86). Crucial to the process was the fact that "The work of the committee was open and public throughout," with the publication of background papers, a newsletter, and workshops held, thereby encouraging participation even from those not immediately involved with the project (86). What this study makes clear is that behind "many disaster-minimizing endeavors is the conviction that ordinary people matter" (Franklin 86). More importantly for the purposes of this thesis, however, is that these examples help us envision a different kind of approach to the field of biomedicine and to the construction of the body story, involving input from a variety of sources.

Based on Elizabeth Fee's account of occupational health research in an Italian factory, Rosser notes how patient involvement in research design and implementation might provide "a mechanism to shorten the distance between the observer and subjects observed" (135). Fee remarks how prior to 1969 occupational health research at this factory was conducted by management appointed specialists; "The procedure was rigorously objective, the results were submitted to management. The workers were the individualized and passive objects of this kind of research" (qtd. in Rosser 135). After the establishment of worker's committees, however, "Occupational health specialists had to discuss the ideas and procedures of research with workers' assemblies and see their 'objective' expertise measured against the 'subjective' experience of the workers" (qtd. in Rosser 135). In this way "the workers had become the active subjects of research, involved in the production, evaluation, and uses of the knowledge relating to their own experience" (qtd. in Rosser 135).

Although Nadler's desire to 'climb the upright tunnel of his microscope' to reconnect with the human side of illness can be seen as a step towards shortening the distance between observer and subject observed, the crucial element missing from Nadler's narrative is actual patient involvement. The expert behind the microscope can choose the distance of the gaze, but the patient does not have the reciprocal option of climbing the upright tunnel of the microscope in the opposite direction. Thus simply shortening the distance of the gaze, although surely an improvement in many ways on the current system, still leaves the patient a passive object of observation and 'military-medical' intervention. Here the role of the paradigm in shaping (and being shaped by) actual social interaction becomes even more apparent, since the SNS paradigm also portrays tissue cells as passive objects of immune intervention. Based on this observation, it will therefore be extremely interesting to follow the impact of the context-based models of immunity (which claim that tissue cells are as, if not more, involved in the conversation as other immune cells) on social interactions.

Even if the medical gaze morphs to become more patient inclusive, however, there is still the issue of basic biomedical research - now both the patient and the expert are gazing at the fragmented body. Thus, although the patient is now included in the process, they are still being asked to consider their body as the sum of parts, some of which (especially on a microscope slide) may appear as though they do not belong. Inviting the patient into the lab may in fact serve only to reinforce the body/mind duality - providing rich imagery of "lopsided," grotesque cellular faces for the nightmares that will follow. It is dubious whether a more holistic image of a complex, interactive body can arise from a prescriptive technology that keeps asserting the autonomy of individual body parts.

Will the portrayal of actively involved body cells that decide the nature of the immune response most appropriate for the situation also affect the ways in which patients and experts relate to one another? Lee's Italian factory example not only shortens the distance between observer and observed, it completely alters the gaze from unidirectional to multidirectional, where both the subjects and the specialists become simultaneously observers and observed. Bringing every cell in the body into the conversation similarly allows for the argument that since tissue cells are the objects of immune intervention, they are also the ones most able to gauge the effectiveness of the intervention. And until patients are actively involved in the medical conversation - and not just where the patient learns to speak the expert language of symptoms, but also where the expert speaks in the language of emotion and social experience - the ability of medicine to deal with illness will be severely limited, and the experience of illness for the patient more awful.

Glossary and abbreviations:

Adjuvant: A substance such as alum (?) that is administered along with an antigen in order to enhance or initiate an immune response to that antigen.

AID: Autoimmune disease

Antigen: Originally defined as molecules that react with antibodies (the name arises from the ability to *gen*erate *anti*bodies), the term has since expanded to mean substances that elicit an immune response (which is also how I am using the term in this thesis).

APC: Antigen-presenting cells are defined as 'highly specialized' cells (dendritic cells, macrophages and B cells can all be APCs) that take in antigens, process them enzymatically into protein (peptide) fragments and display those fragments on their cell surface along with other molecules needed to activate lymphocytes to then seek out and react to those antigens in the body.

Astrocytes: Once thought to be just a component of the supportive structure for neurons, these central nervous system cells might be responsible for the maturation and proliferation of adult neural stem cells, and also for the regeneration of brain or spinal tissue that has been damaged.

Cytokine: A protein made and released by various cell types, most notably lymphocytes, that affects the behaviour of cells bearing receptors for it on their cell surface. It is a crucial component of immune communication.

DM: Danger Model.

EAE: Experimental allergic encephalomyelitis is an inflammatory disease of the central nervous system that develops after mice are injected with neural protein fragments in the context of a strong adjuvant.

Epithelial cell: The epithelium is a layer of cells usually covering connective tissue, typically found on mucous membranes.

IS: Immune system

Leukopenia: Otherwise known as aganulocytosis or granulocytopenia, it is a disease characterized by a marked decrease in the number of circulating granulocytes, namely cells called neutrophils.

Lymphocyte: Usually referred to as white blood cells, lymphocytes are essentially T and B cells that originate from a common lymphoid progenitor.

MBP: Myelin basic protein, or the protein component of the sheath that surrounds larger nerve fibres of vertebrates, allowing quicker transmission of nerve impulses. Demyelination refers to the process whereby, for whatever reason, this myelin sheath is damaged. Remyelination is when damaged, demyelinated nerve fibres are repaired and new myelin is laid down (often an incomplete process).

Meninges: The three kinds of membranes that cover the central nervous system of vertebrates.

Microglial cells: Also glial cells, are a web of undifferentiated cells that literally pack and serve to support nerves cells in the brain and spinal cord.

Mycobacterium tuberculosis: The bacteria responsible for the disease tuberculosis.

Oligodendrocytes: Iron-containing cells in the central nervous system, usually residing close to neurons that are responsible for myelin production.

Phagocyte: Cells such as macrophages or neutrophils that internalize particulate matter (usually bacteria) into special vesicles that then merge with other cellular vesicles containing enzymes capable of digesting the contents.

Recombinant: Typically a protein of some sort (sometimes a whole virus or cell) that has somehow been genetically altered from its natural form, (essentially a word akin to 'artificial' in the biomedical context).

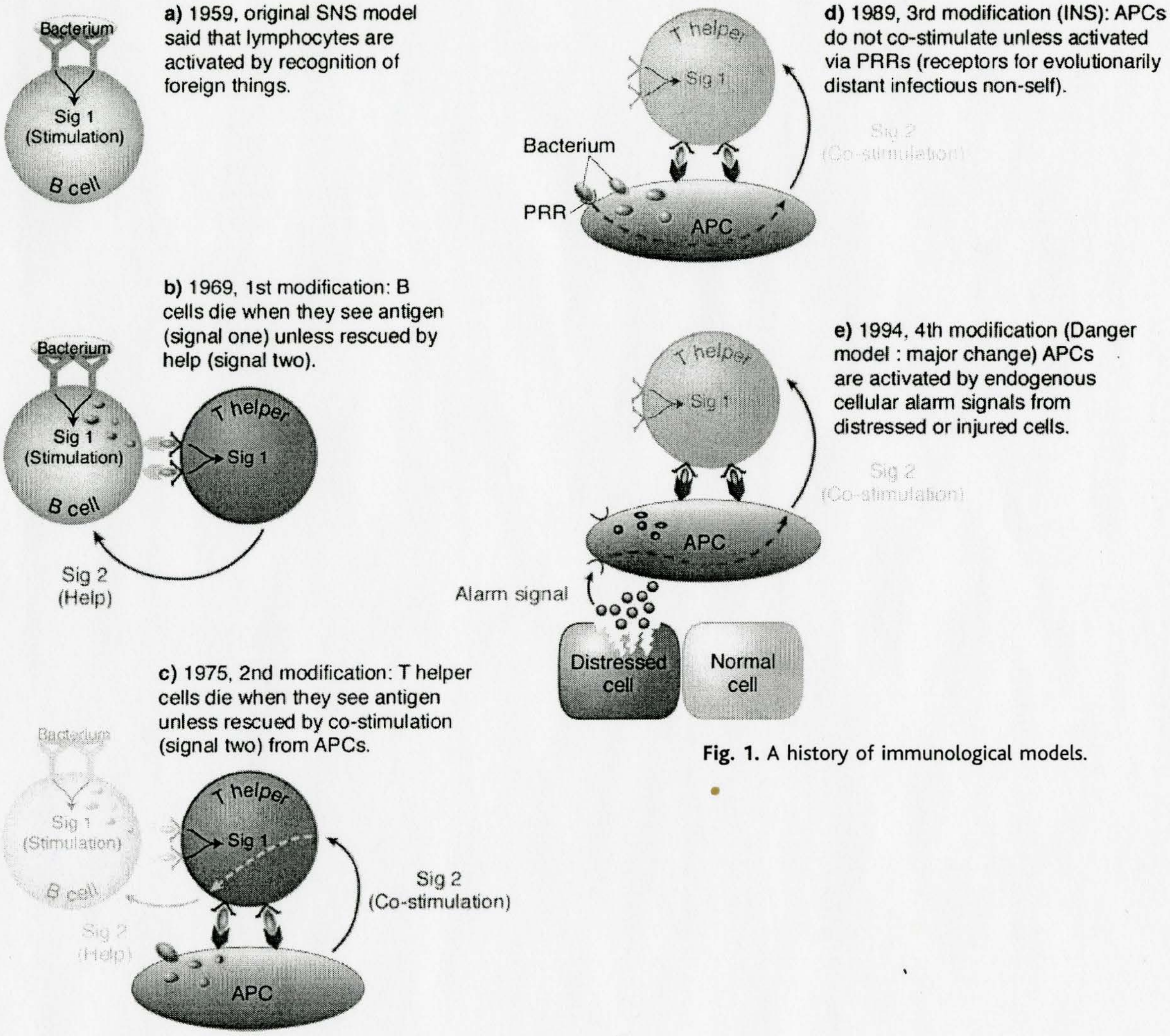
Senescence: The normal expiration of body cells, typically by a process called apoptosis (or 'programmed cell death'), in which the cell activates an internal death program leading to nuclear DNA degradation, condensation of cellular material, and finally uptake of residua by phagocytes.

SLE: Systemic lupus erythematosus.

SNS: Self-nonself.

Thymus: One of the central lymphoid organs, it is a large organ in the upper chest, located just over the heart. In most literature the thymus is believed to be the place where T (for thymus-derived) cells undergo maturation and where self-reactive self are tested and removed.

Trypsin: An enzyme, released as a part of pancreatic juice, that breaks down protein into peptide fragments.



a) 1959, original SNS model said that lymphocytes are activated by recognition of foreign things.

b) 1969, 1st modification: B cells die when they see antigen (signal one) unless rescued by help (signal two).

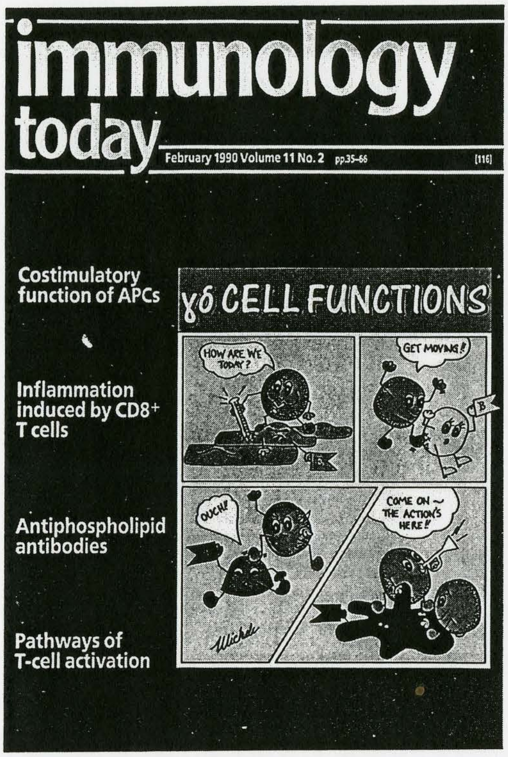
c) 1975, 2nd modification: T helper cells die when they see antigen unless rescued by co-stimulation (signal two) from APCs.

d) 1989, 3rd modification (INS): APCs do not co-stimulate unless activated via PRRs (receptors for evolutionarily distant infectious non-self).

e) 1994, 4th modification (Danger model : major change) APCs are activated by endogenous cellular alarm signals from distressed or injured cells.

Fig. 1. A history of immunological models.

Figure 1.



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Costimulatory function of APCs

Inflammation induced by CD8$^+$ T cells

Antiphospholipid antibodies

Pathways of T-cell activation

γδ CELL FUNCTIONS

Figure 2.

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